



House of Lords
House of Commons

Joint Committee on the Draft
Mental Incapacity Bill

Draft Mental Incapacity Bill

Session 2002–03

Volume II: Oral and written evidence



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The Joint Committee on the Draft Mental Incapacity Bill

The Joint Committee on the Draft Mental Incapacity Bill was appointed by the House of Commons and the House of Lords on Friday 11 July 2003 to examine the Draft Mental Incapacity Bill and report to both Houses no later than four months after the presentation of the draft Bill

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The committee has the power to require the submission of written evidence and documents, to examine witnesses, to meet away from Westminster, to meet at any time, (except when Parliament is prorogues or dissolved), to appoint specialist advisers, and to make reports to the two Houses.

Publication

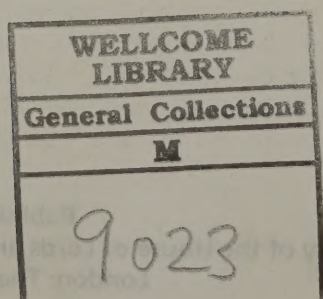
The Report and evidence of the Joint Committee are published by The Stationery Office by Order of the two Houses. All publications of the Joint Committee (including press notices) are on the Internet at www.parliament.uk/parliamentary_committees/jcmib.cfm

Committee staff

The staff of the Committee were drawn from both Houses and comprised Gordon Baker and Sian Jones (Clerks), Francene Graham (Committee Assistant), and Melanie Moore (Committee Secretary). The Committee was supported by the Scrutiny Unit in the House of Commons Committee Office.

Contacts

All correspondence should be addressed to the Clerk of the Joint Committee on the Mental Incapacity Bill, House of Lords, London SW1P 0PW. The telephone number for general enquiries is 020 7219 8387; the Joint Committee's email address is scrutiny@parliament.uk



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Members present:

Barker, B.	Mr John Bercow
Carter, L. (Chairman)	Mrs Angela Browning
Fookes, B.	Stephen Hesford
Knight of Collingtree, B.	Mrs Joan Humble
McIntosh of Hudnall, B.	Huw Irranca-Davies
Pearson of Rannoch, L.	Laura Moffatt
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1. Memorandum from the Law Society of Scotland (MIB 990)

1. INTRODUCTION

1.1 The Mental Health and Disability Committee of the Law Society of Scotland (“the Committee”) welcomes the opportunity of providing written evidence to the Joint Committee on the draft Mental Incapacity Bill. The Committee has been closely involved in the progress of the Adults with Incapacity (Scotland) Act 2000 as it passed through the Scottish Parliament as well as with the related subordinate legislation and supporting Codes of Practice. The Committee therefore hopes that the Scottish experience will be of assistance to members of the Joint Committee when considering reform of incapacity law in England and Wales.

2. BACKGROUND TO REFORM IN SCOTLAND

2.1 The Adults with Incapacity (Scotland) Act 2000 was the first major piece of legislation passed by the Scottish Parliament. No other area of Scots law was in more urgent need of reform. The deficient elements of the previous law caused injustice and sometimes harm to people with impaired capacity, and caused disadvantage and difficulty to families, carers, professionals, managers and others. In some situations the law provided only unduly expensive and restrictive measures, which sometimes imposed legal incapacity in excess of actual incapacity. In other situations there was either no provision, or the law was uncertain, which disadvantaged to people with impaired capacity either because decisions were not taken at all, or matters were handled inappropriately without proper consideration or procedure.

2.2 Prior to reform, some old procedures had been revived and used to meet some needs. For example, the appointment of tutors dative and tutors at law was revived to meet needs for personal guardianship in some cases. These were at best stopgap solutions pending statutory reform, but did give experience of personal guardianship which helped inform subsequent law reform. No equivalent personal guardianship is currently available in England.

3. THE INTERNATIONAL CONTEXT: HUMAN RIGHTS AND NON-DISCRIMINATION

3.1 Reform of adult incapacity law in the United Kingdom follows reforms in recent decades in most developed legal systems. Such reforms have all followed a substantially similar pattern. They recognise that incapacities, circumstances and needs are variable, and that legal incapacity is often partial. They are driven by principles of respect for human rights and non-discrimination. People with incapacities should have the same fundamental rights and protections as others. To the extent that they can, if necessary with assistance, make and communicate their own decisions, this should be respected and facilitated. They should not be disadvantaged by failure to make, or have made, appropriate decisions; but for someone else to make decisions is a limitation of rights and a form of discrimination. Such differentiation should be limited to the minimum necessary, but where special measures are required they should be available. Where someone else is to be authorised to make decisions for a person with impaired capacity, human rights considerations demand that this should follow upon proper assessment, proper determination of what powers should be conferred and upon whom, and that there should be proper monitoring, either by a court or at least with ready and effective access to a court.

4. THE PROPOSED GENERAL AUTHORITY

4.1 It is not clear that the proposed general authority in the draft Mental Incapacity Bill would meet the above requirements. There is no equivalent provision in the Scottish Act, nor would such a provision have been acceptable to any of the organisations within the Alliance¹, which campaigned for law reform in Scotland.

5. THE ADULTS WITH INCAPACITY (SCOTLAND) ACT 2000—PRINCIPLES

5.1 The most important aspect of the Scottish legislation is the statement of general principles in section 1. Effect must be given to the first four principles in any intervention. An intervention means not only the various procedures under the Act, but also the acts and decisions of relevant appointees and others. A decision not to do something can be an intervention. The first four principles require that:

- (i) there should be no intervention unless the intervention will benefit the adult and the benefit cannot reasonably be achieved without the intervention;
- (ii) where there is an intervention, it must be the least restrictive option in relation to the adult's freedom, consistent with the purpose of the intervention;
- (iii) account must be taken of the present and past wishes and feelings of the adult—if they can be ascertained by any means whatsoever, they must be ascertained;
- (iv) and so far as reasonable and practicable the views of the nearest relative, primary carer and other appropriate persons must be taken into account.

5.2 The fifth principle applies to various appointees under the Act: so far as reasonable and practicable, they are obliged to encourage the exercise and development of skills by the adult. Appointees lose the benefit of the Act's limitation of liability provisions if they fail to comply with the general principles.

5.3 In practice, the general principles provide not only a necessary protection for adults with impaired capacity, and a framework for ensuring that appropriate measures are put in place (and appropriate decisions taken) in individual cases, but they have also proved to be very helpful in addressing difficult or uncertain situations. Time and again, reference to the general principles points the way to solutions in cases of difficulty. It is notable that the draft Mental Incapacity Bill appears neither to contain such a clear statement of principles, nor to give such principles equally overriding force.

6. THE ADULTS WITH INCAPACITY (SCOTLAND) ACT 2000—EXPERIENCE TO DATE

6.1 The Scottish Act represents an integrated but not comprehensive code of legal provision in relation to the property, financial affairs and personal welfare of adults with impaired capacity. Implementation was phased, which was necessary for such a major reform, but gave rise to some temporary difficulties because of the inter-dependent nature of the Act's provisions. The first tranche of implementation took effect on 2 April 2001. Further implementation followed in 2002. The final tranche, with a few small exceptions, will take effect on 1 October 2003. The Act's provisions have been generally welcomed, and have achieved significant improvements for people with impaired capacity. In general terms, criticisms have highlighted areas in which further training is required rather than deficiencies in the Act's provisions. Across the range of professions engaging with the Act's provisions, professionals with the most involvement and experience are generally the most positive about the reforms.

6.2 The registration requirements, and supervisory and investigatory provisions, of the Scottish Act appear to have resulted in much better protections for people with impaired capacity. It might be useful to consider the extent to which the draft Mental Incapacity Bill would provide similar protection.

6.3 People with impaired capacity have also benefited from the combination of heightened awareness and availability of appropriate measures.

6.4 Some issues for possible adjustment to the provisions of the Scottish Act have emerged. It may be appropriate in some circumstances for certification under some provisions to be extended to professionals other than medical practitioners. In some circumstances it may be appropriate for certificates under the new authority to treat to have effect for longer than one year. In relation to authority for research, the requirement for consent from appointee or nearest relative presents difficulties where research can only be carried out at very short notice. There is debate about whether (for example) local authorities must obtain an intervention order every time someone lacking capacity to consent is moved from hospital to a nursing home, even where the circumstances appear to be non-controversial.

¹ The Alliance for the Promotion of the Incapable Adults Bill was a group of over 70 organisations who campaigned for reform of incapacity law in Scotland.

7. THE ADULTS WITH INCAPACITY (SCOTLAND) ACT 2000—IMPLEMENTATION

7.1 The new Scottish regime is contained in the Act and several regulations made under it and has been well supported by Codes of Practice, training materials and initiatives, guidance and information published by the Scottish Executive and by the Public Guardian², publicity material including widely circulated posters and leaflets, an active National Implementation Steering Group and other initiatives. For example, there are training courses, seminars and training videos available. These have all contributed substantially to the successful introduction of the new regime in Scotland.

Witnesses: Mr Adrian Ward, Convenor, and Mr David McClements, Member, Mental Health and Disability Committee of the Law Society of Scotland; Ms Elizabeth Craigmyle, Principal Solicitor for ENABLE and Member of the Mental Health and Disability Committee, Law Society of Scotland; examined.

Q1 Chairman: We would like to start this afternoon's proceedings, and I welcome you and thank you for attending. I have some house-keeping points before we proceed to the questions. Even though we have the microphones the acoustics in these rooms are not good, so if you could speak up we would be grateful; we are extremely grateful for the written evidence and the fact that you have found the time to attend; the session is open to the public and it may be recorded for broadcasting; there will be a verbatim transcript of the evidence and you will be able to check the text for accuracy before it is published in the report; as you have already seen, I am afraid proceedings have to be adjourned for divisions in both Houses which may occur and, if divisions occur, I will adjourn for ten minutes; I think there is a note of the Members' interests which are relevant on the table in front of you; and, generally, we are a Joint Committee which is charged to examine the draft Bill. We are not producing a White Paper on mental incapacity, and we have tried to structure the questions which you have seen in relation to the structure of the Bill, and the experience that you have had in Scotland would be extremely helpful to us. Mr Ward, would you start by introducing your colleagues?

Mr Ward: Thank you. I am a Scottish solicitor and Convenor of the Mental Health and Disability Committee for the Law Society of Scotland. We are grateful for this opportunity to come down and we hope that our experience in Scotland will be of some help to you in considering what appears to us to be a rather different piece of proposed legislation before you. I had the opportunity of preparing the first draft of our memorandum of comments and I take it we can take that as read. If so, I am going to introduce my two colleagues. Two matters were not fully covered in that memorandum: firstly, just what in simple terms the Scottish legislation does encompass and David McClements will say a few words about that, and you may have picked up from our memorandum the importance of our general principles, and Liz Craigmyle will say a few words about that.

Mr McClements: Our Act has seven parts to it. Part 1 contains the general principles, but in addition it contains the roles and responsibilities of different agencies operating under the Act. Part 2 deals with the creation and exercise of continuing powers of attorney and welfare powers of attorney.

This part sets down the main obligations on attorneys, the powers of the court and the role of the Office of the Public Guardian. Part 3 created an authority to intromit with funds belonging to an adult. It can only be used to access funds in a nominated bank account, and its operation is controlled by the Office of the Public Guardian, to whom the intromitter is accountable. Part 4 makes provision for the management of finances of an adult by a registered establishment. This will become operational from October of this year. By regulation a limit of £10,000 has been set for this type of management, and monitoring again is exercised by a public body, the Care Commission. Part 5 establishes the authority to treat by medical methods with appropriate certification other related matters, including the authority for research. Part 6 creates intervention orders and guardianship orders, both for financial and welfare matters. Intervention orders were proposed by the Scottish Law Commission for the purpose of one or more orders which may not have ongoing purpose. The functions of guardians are detailed in this part of the Act, together with the methods by which their actions are supervised. Finally, Part 7 deals with a miscellany of issues such as transitional arrangements from pre-existing law and the creation of the new offence of ill treatment and wilful neglect.

Ms Craigmyle: The new Millennium heralded the beginning of exhaustive on-going multi-disciplinary training relative to the then Bill, and now the new Act, and everyone was, and still is, on a steep learning curve. Training events ranged from hundreds to only a few participants and they included adults with incapacity, those with learning disability, with mental health problems, with head injury, with dementia. Trainers emphasised that, if nothing else, participants should leave the event with the gateway principles foremost in their minds. If they wished to intervene in the life of an adult then these principles, the first four of which are enshrined in the Act, must be met, and arguably the fifth principle should also be enshrined. The principles are simple: they are the principles of benefit, past and present wishes, views of relevant others and least restrictive intervention and, finally, encouragement of skills. Extensive accessible training materials have been produced by the Scottish Executive, the Office of the Public Guardian, voluntary agencies such as ENABLE, SAMH and ASAD. Websites carry

² This information is also readily available on their respective websites plus URL. <http://www.publicguardian—scotland.gov.uk> (Public Guardian) <http://www.scotland.gov.uk> (Scottish Executive).

10 September 2003 Mr Adrian Ward, Mr David McClements and Ms Elizabeth Craigmyle

extensive regularly updated guidance. The executive introduced amongst its material an aide memoire in the form of five principles printed on a credit card sized card which was very popular. The perfect piece of legislation does not exist but the Adults with Incapacity Act has generally been welcomed and embraced as an empowering piece of legislation with the emphasis very much on the adult's capacity. It has increased the profile of independent advocacy, and it has given many vital voices a voice.

Q2 Chairman: Thank you. If I can start, what advantages are there in requiring evidence of a defined mental disorder as a diagnostic threshold above and beyond a test of a person's capacity?

Mr Ward: I think the general pattern of legislation of this type is to have a fairly wide gateway which enables one to access the legislation and then careful controls before one actually intervenes. At the stage of the gateway where one can potentially access the legislation, I note differences between your draft Bill and our Scottish Act in two areas. First of all, yours has a gateway of mental disorder. Ours has a gateway of mental disorder and physical inability to communicate. I think there are potential difficulties in your narrower gateway—for example, an advance statement operates during incapacity, if incapacity means only incapacity through mental disorder. It would not operate where there was a complete physical ability to communicate. Secondly, our definition of incapacity relates to incapacity both to act and to make decisions. I have difficulty in following your draft Bill which has a definition of incapacity relating solely to making decisions, yet for example under the general authority only permits acting which makes one wonder whether that means an Act that excludes a decision? What does it mean?

Q3 Chairman: I am not entirely clear. If you have in Scotland a mental disorder but you can communicate, how is that caught by your Act?

Mr Ward: There are two gateways, in effect. The broad and most common one is mental disorder which has a wide definition and is the same definition as in our mental health legislation. It covers most situations, in fact, of incapacity other than the situation of a complete inability to communicate for physical reasons. We have that gateway also.

Q4 Chairman: Would that mean if somebody, for example, had no mental disorder but was deaf blind and could not communicate, they would still be caught by your Act?

Mr Ward: They might be but only if they were completely unable to communicate because another feature of our Act is an absolute obligation that if someone can be communicated with, or even if they have incapacity if their wishes and feelings can be accessed by any means whatsoever, they must be accessed and at the level of capacity we only have incapacity through inability to communicate if that cannot be done at all. It is the same with wishes and feelings. I do happen to know that one of your witnesses in the second batch from Scotland who is

quite well known to me has written some very interesting papers on accessing the thoughts of people who would appear to most of us to be totally unable to communicate. In Scotland now, if it is possible, even if only with very skilled assistance to communicate, we must.

The Committee suspended for a division.

Q5 Chairman: Firstly, I apologise. I am afraid this is going to happen again. It is at the time of year when both Houses are extremely busy, particularly the Lords. To continue, it has been pointed out to me on the point made about the difference between the two Bills that in the draft Bill, in clause 2(3) it says, "A person is not to be treated as unable to make a decision unless all and practical steps to help him to do so have been taken without success" Does that meet the point you were making about the difference between the two Bills?

Mr Ward: I think the language in the Scottish Act is just a little stronger on the equivalent point. Our Act says, firstly, on the inability to communicate, "A person shall not fall within this definition by reason only of a lack of deficiency and a faculty of communication if that lack or deficiency can be made good by human or mechanical aid, whether of an interpretative nature or otherwise."

Chairman: I see. That is an interesting comparison which we will take on board.

Q6 Stephen Hesford: In our draft Bill there is a presumption of capacity which I see as very important. Do you have the same presumption, and is it spelled out on the face of your Bill?

Mr Ward: We have a strong presumption of capacity in our law, anyway. Unless my colleagues correct me, we do not need that presumption because we have our principles so tightly limited in any situation in which we would intervene anyway. I mentioned earlier the gateway—the gateway is incapacity. There has to be incapacity and then we still do not do anything, we do not intervene, unless very stringent principles are satisfied.

Q7 Stephen Hesford: From what you were saying before, is that seen as a positive or as a negative, to access something that you otherwise would not have because of your incapacity?

Mr Ward: What I have termed the gateway is a positive. The concern in debate was that we should not exclude anyone who might potentially benefit from the Act's provisions, so at the level of the gateway we want the broad gate where we have it, but before we intervene, before we apply the Act's provisions which is immediately discriminatory—we are doing it for the best of reasons but we are dealing with somebody differently because of their disability and to some extent taking away their right to act or make decisions and putting some other mechanism in place—it is restrictive and a very stringent test.

Q8 Mrs Browning: In the Bill before us capacity assessment seems to be based more on a functional approach, whereas in the Scottish legislation you

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seem to have a little menu of clearly defined descriptions of mental disorder, including, I note, any mental illness, personality disorder and learning disability. I would be very concerned about that and would like to make two points: firstly, the actual writing in of personality disorder on a Bill—which I think is extremely difficult to define, not least because it is a spectrum—and also how much you define in Scottish law “learning disability”. Is that based on the old IQ test? How do you define that?

Mr Ward: Liz is from ENABLE and is a specialist in learning disability, so she can answer the second part of your question. My personal view has always been that I have had some concern about personality disorder and such a definition for the reason you give. One could say that probably almost every personality has its little disorders somewhere within it, and some to a rather greater extent, but in the context of capacity legislation, for the reasons I have given, that is not a great problem because we are not applying any provisions to anyone just because they come within that definition. We only apply them if they come within that definition, and then the principles are satisfied.

Ms Craigmyle: On the learning disability front, our law historically refers to mental handicap which is now resisted in this day and age, and the definition that my organisation tends to use is “related to birth” or “shortly after birth” but we recognise that there can be acquired learning disability also through head injury or progressive genetic conditions, of which there are many. I recognise the difficulties, however, in what you are saying about the definition of learning disability and how it is perceived, but it is in there and on the face of incapacity as we have it.

Q9 Lord Rix: In terms of learning disability, has the Act made a great deal of difference to people with learning disability, as such? Has it made a difference yet to carers? Has it made a difference to staff or professionals? Has it helped in any way to make their lives better at this stage?

Ms Craigmyle: Yes, I believe it has made a difference. The training events have been pretty exhaustive, as I said in my opening statement, since the beginning of the Millennium and they are ongoing. Much of my training is to carers or to people with learning disabilities themselves and there were many good things to come out of the big initial training events, the ones with over 100 attending each event in a multi disciplinary sense. One of the things that they focused on was that much could be learned, if you like, from the coal face, and those involved in caring or people with learning disability themselves were the ones who were being proactive in making sure the professionals involved in the life of a person with a learning disability became aware of the content of the new Act and of what it could mean to that person and to their carers. For the very first time in our legislation it gave an empowerment to carers to have a voice and to interact and talk to the doctors primarily responsible—normally that would be GPs but it could be a consultant—and say to them, “Here is what I know about the adult; here

is the adult’s best and worst performances; I see him or her on a good day and a bad day and here is what I think the adult is capable of.” Generally I feel very much that it has enhanced, people are embracing it, it is not perfect but it is welcomed, and they are as comfortable at this moment in time as they can be with it.

Q10 Baroness McIntosh of Hudnall: You mentioned earlier on in your evidence that there was some degree of overlap between the mental health provision and the mental incapacity provision particularly in the definition of disorder. Do you think, drawing on your experience, that it is necessary to have separate legislation for mental incapacity and for mental health, and would, in your view, the coherence of implementation in those areas be improved if the two areas were combined under one legislative framework?

Mr Ward: Firstly, what is mental health law? In Scotland our Mental Health Act has always been rather narrower than the English Mental Health Act. The English Mental Health Act contains in Part 7 a lot of financial management provisions which we would class as incapacity matters, not Mental Health Act matters, so there is a question of definition. Back in 1986 I think I was the first person to suggest to the Scottish Law Commission that they should carry out a comprehensive review of incapacity law and mental health law. Having recorded that, I would say that I do favour the separate treatment of the two areas involved because they are two different subjects. Mental health law in its core sense is to do primarily with forms of intervention, compulsory intervention. Incapacity law is quite a separate matter: it is to do with addressing the difficulties which some people may have in acting and making decisions for themselves across a wide range of purposes. We have had recent reform of both: we now have a new Mental Health Act on the statute book about to come into force. We had two separate processes of review and consideration, but very much in parallel, very much linking to each other, and I think even down to questions of terminology there is a risk of confusion between the two. There is confusion on your door here which talks about the “Mental Health Incapacity Bill”!

Q11 Baroness Knight of Collingtree: I think it could be said, Mr Ward, that our major job on this Select Committee is to see how and in what way we can improve the draft Bill, and on that point I would just like to ask you two quick questions. Firstly, might the inclusion of some explicit general principles improve the draft Bill, and I also want to ask you about the best interests test. Does this test, do you think, provide the necessary protection from abuse for adults with impaired capacity? I think that question is important to put to you because I think you considered the concept of best interests was inappropriate in Scotland in relation to decisions made on behalf of adults with impaired capacity. Could you comment?

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Mr Ward: Our general principles, absolutely, are serving us well. They appear at the outset of our Act: they apply to any intervention which can mean a decision by a court, a decision by somebody with some form of authority, a decision by someone acting anywhere in the process that may confer authority, a decision not to do something is an intervention, and our principles apply really throughout the whole legislation. They are a major safeguard and also a very considerable help. Because I specialise I tend to get difficult issues coming to me, and very often if one sits down and says "Just a minute, test this against the general principles", you are well on the way to the best answer. If I were making recommendations I would recommend the concept of much stronger general principles with overriding force. Ours apply to the extent that the exclusion of liability provisions in our Act do not help you if you breach the principles. Secondly, on best interests, there was consensus, I think, in Scotland that this was appropriate in child legislation and not in adult legislation. The best I can probably do is refer you to what the Scottish Law Commission said on the subject. They basically adopted a principles approach rather than a best interests approach, and if you would bear with me for a moment because I think this is quite important I will read what they said. "Our general principles do not rely on the concept of best interests of the incapable adult. We consider that "best interests" by itself is too vague and would require to be supplemented by further factors which have to be taken into account. We also consider that "best interests" does not give due weight to the views of the adult, particularly to wishes and feeling which he or she had expressed while capable of doing so. The concept of best interests was developed in the context of child law where a child's level of understanding may not be high and will usually have been lower in the past. Incapable adults such as those who are mentally ill, head injured or suffering from dementia at the time when a decision has to be made in connection with them, will have possessed full mental powers before their present incapacity. We think it is wrong to equate such adults with children and for that reason would avoid extending child law concepts to them. Accordingly, the general principles—which they set out—"are framed without express reference to best interests", and I was reading from paragraph 2.50 of the Scottish Law Commission Report on Incapable Adults.

Q12 Baroness Knight of Collingtree: In addition to those important points that you have put to the Committee, would it not be appropriate also to point out that judgment on what is the best interest, for all sorts of reasons, can vary very considerably indeed?

Mr Ward: I have proposed in some of my writing almost a hierarchy of decision-making. At one end we have the adult's competent decision. We may be able to get a competent decision from someone with impaired capacity about parts of a composite decision. We may have clear wishes and feelings from them, and some of these are instinctive. We see

proposed very complex mechanisms for assessing decision-making capacity. If we think about it, the most important decisions in life we tend to make instinctively—the career we follow, who we marry, the sort of place we like to live in. Can we really pick up some of these rather theoretical methods of decision-making and apply them to those decisions we make? We make decisions instinctively and we make them on a habit basis. Somebody who may be quite impaired in capacity may always choose tea rather than coffee when offered it because they always have done. In many ways you might say they are incompetent but that may still be a valid decision. We then can build up a picture of what somebody's ethos is from their family and friends and someone unrelated to them. Deciding what is in their best interests, in my view, is almost at the end of the hierarchy of possibilities. If we have no information about the person then perhaps the best we can do is for me to say, "Well, what is in your best interests?", but on dealing with adults my own view is that that is a fundamentally unsatisfactory approach.

Q13 Huw Irranca-Davies: I can understand the reasoning behind the differential between adults and children but do you think there is any case to be advanced as we look at our legislation for extending that into, if you like, the grey area of the 16-18 year olds?

Mr Ward: Our adults are adults at 16. Our child law effectively stops at 16 and our Incapacity Act definition of an adult is someone who has attained the age of 16. Basically the thrust of Scots law is that adulthood starts at 16 but for some purposes is qualified up to 18, so probably our experience is not going to be so helpful.

Q14 Mr Bercow: I understand your concern that adults should not be patronised, Mr Ward, but in order that it is not merely—as I am sure it is not—just a semantic dispute, could you for my benefit give what you think is the best practical example of how the benefit criterion is more appropriate than the best interests criterion?

Mr Ward: I think it is, for instance, somebody living in very odd and in many ways unsatisfactory circumstances, and in a very poor form of accommodation. In our approach you would say, "Is this what they have chosen? Is this where they have always been living? Is there really a benefit to that particular adult in taking them out of where they have chosen to be?", whereas if, with no knowledge of that person, you and I walked in together we might well agree and say, "Goodness me, their best interests might be that we should get them out of here right away."

Q15 Baroness Fookes: But best interests in our draft legislation is qualified in a number of ways, including the person's wishes. Does that not make a difference? It is not best interests on its own, is it?

Mr Ward: It helps to make some difference but it is still the starting point. We start with principles.

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Q16 Mrs Humble: I was going to raise a very similar point because you said in your objection to best interests that you would then have to be qualified in a variety of ways and you would have to expand upon it, and of course in the draft Bill it is expanded upon because there is a checklist. Does that checklist answer your problems? Does it deal with the problems that you believe arise from the best interest description? Does that checklist reflect the statement of principle that you have in your legislation?

Mr Ward: I do not think it does to the same extent, no. Language is important and it still does start with the concept of what is paternalistically in this person's best interests, and I think compared with our principles our principles are stronger and more focused on the adult as a person and on non intervention at all, unless it is clearly shown to achieve a benefit and to be the least restrictive.

Q17 Stephen Hesford: Is there a practical concern based on previous experience, ie before the implementation of your newish Act, what my colleague over there called a patronising view, because sometimes when one deals with a carer one feels that, with the best of intentions, the carer is taking decisions which ultimately could be said to be in their best interests as a carer rather than the person that they are caring for.

Mr Ward: That is why our legislation has nothing equivalent to your startling proposition of a general authority!

Chairman: I think we are coming to that later on.

Q18 Stephen Hesford: But, in terms of best interest, is there any evidence or example that your method addresses that potential problem?

Mr Ward: Our comparison and experience obviously has to be a comparison between what we experience now and what we were experiencing before our Act was introduced.

Q19 Mrs Browning: To follow up, I agree that there are very often times when carers put a point of view that is perhaps their view and their interest rather than the person they are caring for, and I say this as a carer myself. There are also times, however, when the carer, up against "authority" for want of a better word, finds that authority's view is based not on anybody's interests but on the resources they have to hand at any given day of the year. How do you deal with that?

Mr Ward: By applying our general principles rigorously to both.

Q20 Mrs Browning: You must have more resources than we have, then!

Mr Ward: Yes. I suspect that more often the principles have been used to give authorities a hard time than they have been used to give carers a hard time, but to a certain extent the approach is objective and there is the obligation to take account of the relatives and primary carers' views. Anybody making a decision has to do that.

Q21 Laura Moffatt: I am interested in the comparison. We are trying to tease out on this Committee the difference between what you clearly see is the benefit of not having just a general view and the fact that there must be a benefit to a particular person if you are to achieve the outcome you are looking for. This prelegislative scrutiny has attracted a lot of attention—perhaps unfairly—because some people have focused on the problem of artificial feeding and hydration as one of the basic things we are attempting to deal with. We see that as not being true and probably unfair, and we need to broaden people's aspects of what we think we are trying to do here and try to get them to understand it is much wider issue. But could you tell me under the Act that you have how you would describe withdrawal of artificial hydration and artificial nutrition as a benefit to that particular person?

Mr Ward: Firstly, I should point out that while refusal and withdrawal of treatment was a topic included in the draft Bill for Scotland prepared by the Scottish Law Commission that was dropped by the Scottish Executive in our legislation, so we have had the benefit of discussion and consideration of that point in the lead-up to our legislation. Because of that I can answer the second part of your question and I may come back to first part. It was never envisaged that we would be saying that to withdraw some form of medical intervention would be a benefit. The result that our principles produce in that situation would be to ask the question, "Is the medical intervention a benefit? Is the provision of the artificial feeding or hydration a benefit?" If it is judged not to be a benefit or to have ceased to be a benefit, it is that intervention which is no longer justified and is not given or is withdrawn. So there is not a benefit in withdrawal, but the provision or the treatment which is the intervention may cease to be a benefit.

Q22 Laura Moffatt: But when questioned before you said that not taking action was a legitimate intervention?

Mr Ward: Yes.

Q23 Laura Moffatt: So that gives it equal status?

Mr Ward: Yes, but that is the view the Scottish Law Commission took. They recognised the difficulty of the point, and that is the approach they took.

Q24 Baroness Knight of Collingtree: The BMA recently decided that they would call giving food and liquid through all these methods "treatment". Has that altered your own way of managing affairs of this kind, because there is a great deal of concern about the fact that, being called "treatment", feeding people can be disallowed or stopped.

Mr Ward: I am aware of that debate: I do not think that the issues of terminology are having an effect of which I am aware in Scotland, and these are essentially issues of terminology. I am aware that some legal systems, not British ones, make a clear distinction between the care and treatment and I do not think we tend to in the United Kingdom. I do not know if my colleagues agree?

Mr McClements: I think we agree with that.

Lord Rix: Is there not case law in this regard?

Q25 Chairman: I was about to ask that. Would the *Bland* judgment, which I think has driven the BMA view, have any influence or effect in Scotland? If there were a case brought to court about withdrawal of treatment, would the decision of the Law Lords here in the *Bland* judgment have any effect?

Mr Ward: We tend to look at a case called the *Law Hospital* case in Scotland, which is the name of the hospital where the lady was, and that is our leading case on the subject. Part of the reason why this topic was not carried through into our legislation is that that case arose after the Scottish Law Commission had reported, and the Court of Session provided some very clear guidelines on when they considered that withdrawal or termination of treatment might be appropriate and on procedural aspects as well, so we have switched to a judicial development of this area of law. The official reason given by the Scottish Executive for not retaining such matters in the legislation is that "attempts to legislate in this area will not adequately cover all situations which might arise and could produce unintended and undesirable results in individual cases".

Q26 Chairman: Does that mean they are leaving it to the courts to decide?

Mr Ward: Yes. The courts have greater flexibility and it has been left to the courts.

Q27 Chairman: It is the Scottish equivalent of common law, in effect?

Mr Ward: Yes, based on the *Law Hospital* case which you could say in rough terms is the Scottish equivalent for us.

Q28 Chairman: That is very helpful indeed.

Mr Ward: I am not saying that is necessarily a view I would personally advocate, but that is what happened in Scotland.

Q29 Baroness Fookes: Could we ask what you do advocate, then?

Mr Ward: Both on this and the other topic that was dropped from the Scottish legislation which is the question of advance statements I think I would have preferred the clarity of putting these into legislation and having it as part of the scheme of the legislation so the interrelationship of these elements would have been clear, but I would have hesitated because there is quite a degree of force in the argument that, if a subject is developing fairly rapidly and, for example, views on what is and is not treatment are changing, there is certainly a very stateable argument that it is better to let the courts respond and develop principles for a little longer before fixing the matter in legislation. I am a little ambivalent about it and I can see the arguments both ways.

Q30 Chairman: We have had an enormous number of submissions of concern over this aspect of the Bill. Did you have the same concern in the consultation period and in the drafting of your Bill?

Mr Ward: Yes. I was principal spokesperson for an alliance that was campaigning for the Bill. It was quite a substantial organisation and we had more than 70 organisations in it with over 30 national organisations. We had great difficulty over these topics and I believe that, in fact, that difficulty was part of the reason for dropping some of them. They really almost hijacked the agenda. Those who had strong views were using our legislation to have an argument about those views which was not relevant to what appeared in the draft Bill, but the argument was loud and it did threaten to draw attention away from the vast bulk of the provision.

Q31 Baroness Barker: Following that up, is the consequence of that decision that you will, for the foreseeable future, rely on case law?

Mr Ward: In the matter of advance statements and in the matter of withdrawal and termination of treatment, yes.

Q32 Mr Bercow: We have had more of an inkling of your thinking on the next subject, I know you will want to elaborate on it. How adequately, if at all, is the scope of the general authority defined in the draft Bill or is it too little circumscribed? How do you recognise it will work in practice and tacked on to that, and related, how useful is the concept of reasonable belief in the capacity?

Mr Ward: The idea of a general authority fills me with dismay. If somebody thinks my capacity is becoming impaired they can do what they think is best, they can act. What does it mean "they can act". I cannot see how that can be compliant with the European Convention on Human Rights. If somebody is making decisions about me or for me they are taking away my right, albeit for very good reason, they are taking away my right to make those decisions myself. Quite clearly under Article 6 of the European Convention that should only be done with the authority of a court after a hearing.

Q33 Mr Bercow: The issue of liberty and consent is extremely important and I do not grapple with that but just to elaborate, do you think in practicable terms if we were to ignore Mr Ward's advice and say "he can do what he likes in Scotland, we think that we have been advised sufficiently in the draft and we can go ahead as we think fit", there is going to be a ream of damaging practical cases that will result and cause us to repent?

Mr Ward: In some of your papers I saw a figure that the Master of your Court of Protection quoted, quite a high percentage of cases of powers of attorney where he believes there was abuse, there was misuse of powers. That is quite a high percentage in a situation that is already regulated and known about. I think if one confers that authority to do what they like on people who are not regulated, not known, not supervised the risk of misuse of that authority will be grave. One thing that is clearly lacking from that, even compared with the most simple procedures, is the most simple protections. We have very simple procedures in our legislation which requires somebody to say, "Just a minute, is this person's

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capacity impaired? Is it impaired to a degree that they cannot act or decide in the particular matter that we are addressing therefore do we need to put in place a procedure?" I suspect that the general authority will stop people even considering such a point. It will be used retrospectively as a justification for what has occurred.

Q34 Mr Bercow: And administrative convenience will end up taking precedence.

Mr Ward: Everybody's convenience. Of course there will be many, many people who will exercise it very wisely, very sensibly and very responsibly, but it would be equally easy to proceed otherwise.

Mr McClements: I was just going to add to Mr Ward's comment, I think a practical problem could well be general authority, where an individual engages with a third party organisation in terms of being able to show clearly that they actually have the authority that I mentioned in the opening statement. We have a section, part three, which deals with financial institutions. I have great concerns as to how financial institutions would view and recognise somebody who claims to have general authority and how they would deal with that.

Q35 Baroness McIntosh of Hudnall: I think it is pretty clear that there are certain aspects and general authority principles that are open to question. On the whole what you have said is viewing the position from the standpoint of the person requiring care, the incapacitated adult. There is another aspect to it, the protection it affords to the carer, in other words it frames the carer's action but it may not do so entirely adequately. Can you explain in what way carers within the Scottish legal framework are protected in relation to actions they may have to undertake in certain circumstances there and then on the day, as it were, which could retrospectively be construed in a particular way? In what way are they protected within your framework?

Mr Ward: I am going to answer your question to start with slightly obliquely, to a large extent the move for reform in Scotland started with carers. We started by trying—and I mentioned this in our memorandum—to use our common law principles in modern ways, providing procedures to create formal guardianship. This was driven typically by the parents of young adults with learning disabilities who were saying, "we know we are making these decisions, we are ordering our children's lives, we have no authority, nobody has thought about what we are doing, nobody is controlling whether what we are doing is appropriate and because we are doing it that way also when we are dealing with authorities we are just another adult in the same house". To a large extent those developments which were the precursors of our reform came from carers because they were worried about these aspects. I think there is all the difference in the world between making representations about the living conditions or life-style or activities of your young adult learning disabled son or daughter living in some accommodation under somebody else's care because you have welfare guardianship powers which

authorise you to make such decisions, and you always have to obey the general principles, compared to being just a parent trying to have something done because you do not think the way it is happening is appropriate.

Q36 Lord Rix: Under your Act how do the actual powers which you give to the parents of learning and disabled young adults operate, do you have to go to court to seek them?

Mr Ward: If one is looking for guardianship powers, yes, you have to apply to the local Sheriff Court. If we are seeking welfare powers we have to produce a couple of medical certificates, one of which is required to be from a consultant psychiatrist, we have to give notice to the local authority, whose mental health officer also produces a report. These reports are submitted. The whole process is governed by the general principle, so one has to justify each power sought on the benefit and intervention basis and on the other principles. The guardian will then have some powers tailored to the circumstances and abilities of that particular adult, even with those powers the guardian must then continue to apply the principles so they use them in a manner consistent with the principles.

Q37 Lord Rix: Have there been many powers granted of this nature as yet?

Mr Ward: David may have some statistics, I did not bring those.

Mr McClements: The statistics for the first six months in relation to appointments of welfare guardians are as follows, there were 72 appointments in the first six months, from April 2002 to September 2002, with 108 pending at that stage. There has been continuing development in that, there have been more cases. It may be interesting in relation to the statistics that the number of powers of attorney—the power of attorney is the capability to grant welfare power of attorney—in the first 18 months of registration were 3,890 continuing powers of attorney, lasting powers of attorney and an additional 1,439 which had joint powers of welfare and continuing powers.

Mr Ward: And 189 purely welfare.

Q38 Lord Rix: Does ENABLE think that is sufficient for the time that has elapsed since the passing of this Act?

Ms White Craigmyle: We probably think it is. It is important to point out there are of course those people with learning disabilities who understand a power of attorney and even understand possibly with some support. In my legal practice with ENABLE we have assisted 15 individuals so far with learning disabilities to enter into the granting of a power of attorney themselves in favour of an individual of their choosing. Usually more support is needed for people with learning disabilities but if we are in doubt of course we consult with the relevant GP or doctor. Given the passage of time, yes, I think the statistics that David has quoted are reasonable.

Q39 Huw Irranca-Davies: I have listened with great interest to your comments on general authority and your strong reservations about it. I was going to ask you in respect of Clause 7 of the draft legislation we have in front of us whether you thought the restrictions on the use of general authority were adequate? I suspect your response is going to be that the fundamental premise of the general authority is flawed in such a way that the restrictions themselves are unworkable?

Mr Ward: That would be half my answer. The other half was one I alluded to earlier. I do not know what is authorised. It is lawful for any person to do an act, not to make a decision. You make the distinction between decisions and acts, what acts are not decisions? Some things are more clearly acts and some things are more clearly decisions, acting to safeguard your interests in a more general sense is acting, it usually comes down in implementation to making decisions. Not only do I have reservations about the concept altogether, but I find it difficult to look at the restrictions because I do not know what it is that is being restricted.

Q40 Huw Irranca-Davies: In your expert opinion what would be the practical implications of going forward currently with the general authority as it is and then trying to impose restrictions? How would that be tested? Could that be tested effectively? Would it work?

Mr Ward: I am sure you would have lots of litigation for at least a decade. I am not sure that of itself would be something that you would want to do knowingly.

Q41 Huw Irranca-Davies: Are you convinced of that?

Mr Ward: Pretty sure. In some ways if there was not lots of litigation I would be even more worried because people would just be going ahead and using the general authority in all sorts of situations, appropriate or inappropriate, without challenge. I would emphasise part of our provision, which is a coded provision, a comprehensive but not exclusive provision, includes investigatory provisions. The Office of the Public Guardian in Scotland is carrying out investigations in any situation where it is suggested to him that the financial interests of an adult are at risk and it is not just related to particular procedures situated where a power of attorney is in place, local authorities have an equivalent duty where welfare is at risk and you get joint investigations. We have these investigatory powers and they can be matched up with the public guardians and all forms of authority under our legislation which have been granted which are not just guardianship and intervention on the simpler forms which David has described.

Mr McClements: The other concern I would have is that in relation to general authority, and I do not think Adrian has touched on it, is the difficulty you might have between individuals, it is almost presumed there is one carer. If there are different carers expressing different views and indicating they

have the general authority it is just a recipe for conflict in what is already a difficult situation for them and things will be made much more difficult.

Q42 Huw Irranca-Davies: Clause such as Subsection (2), "the general authority will be 'trumped' by a decision of a donee of a lasting powers of attorney or of a deputy", that is not sufficient to calm your fears?

Mr McClements: I do not think so because that presumes that someone has a power of attorney. We are talking about somebody who is subject to general authority, then it could be two or three individuals that are suggesting "I have general authority". I come back to the point I made about financial matters, I cannot see how that is going to work in practice. Where this is coming from in terms of provision of any form of care is at one level one can understand where it is coming from in terms of time to meet the needs of carers but I think our concern is that in all this that it is in the best interests of the draft Bill to benefit, as we have in our act, is the adult or the person, that it is their interests, whether it be in terms of benefit or best interest. The general authority is coming from the other standpoint, to make it easier for carers. I have grave doubts about that in its present form. One other point I just want to make is that I think there is a distinct lack of any definition of care. That again means that the whole concept of general authority is open to great confusion.

Q43 Chairman: Under your system is there a risk you will see over-prescriptive powers to avoid going back to court each time an order is needed? What authority do carers have without a guardianship order? Are carers without a guardianship order acting without the power to do so under your system?

Mr Ward: If an applicant is coming along seeking powers which cannot be justified by reference to the general principle they will not be granted. One does find oneself in discussion in an application sometimes just how far to take the powers. One tends to work on the principle of powers reasonably expected to be needed. If you go beyond that covering possible situation the court will be unlikely to grant them. You can always go back for variation of the powers, the procedure for that is simpler. If you are varying financial powers or you are varying welfare powers you are proceeding under a variation procedure. If you seek to have financial guardianship extended to include welfare powers do you have to begin at the beginning and go through the court.

Q44 Chairman: If there is no guardianship order what is the authority that the carers are working under?

Mr Ward: They have no statutory authority. This is an issue which has arisen.

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Q45 Chairman: They would have under our Bill.

Mr Ward: They would have under your Bill, yes. First of all in medical matters our doctrine of necessity survives and unimpaired. Generally our Act does not take away any principle which exists in law already. The principle of necessity, certainly in medical matters, may cover us and it may extend to some non-medical matters. The strong pressure under our legislation is that if you perceive that you are going to need to exercise powers then, get proper authority to do so. In financial matters you can do that very simply. In medical matters a doctor can do it very simply: it requires one simple certificate which involves no more than the matters under good practice you would have to address anyway.

Q46 Huw Irranca-Davies: Can I ask another question which is to do with the use of force in two aspects, one is the restriction or misuse of force and the restriction of liberty from an individual's point of view, but also from the carer's point of view, that there is a reasonableness about the way which we approach the way they use force. I am thinking particularly of dementia where there is a safety risk to the individual that is being cared for. It could be argued that in that situation that the carer should be able to use a certain amount of restrictive behaviour to avoid getting into a perilous situation. How does your legislation deal with that?

Mr Ward: I think our general law covers both situations. If I see you stepping off a pavement in front of a bus and grab you and pull you out of the way I am not assaulting you but if I did that in any other situation it would be. That is the level at which we have cover, and only at that level, not in our legislation.

Q47 Baroness Fookes: Could I ask about what I would describe as casual care, in a sense the good neighbour living next door who may do things for somebody but probably not think of getting

authority in your system, what happens to that person who may go out and do shopping and have to pay for it and then maybe take the money from the person?

Mr Ward: We do have a principle in Scots law that long predates our Act and has not been set aside by the Act which is a the form of agency of necessity and that still applies. The difficulty is that one does not have the authority, so if you then go along to the bank with a bank book they may say, "what authority do you have to do this?"

Q48 Baroness Fookes: I was thinking about something more casual, shopping and taking the money out of the purse, that kind of situation, not to unlock a bank account.

Mr Ward: This principle covers that but there is an element of risk and the risk is to the person that is doing that too. Under our system it is not very difficult, you do not have to go and see a lawyer if you want to access somebody's bank account to pay their bills for them and meet their financial needs. You get a form from the public guardian, he will give you any amount of help, he will even let you do it electronically, he will talk you through it over the telephone. You need a certificate from a doctor and you need a certificate from somebody who knows you and the person, you send them off and you will get a certificate of authority.

Chairman: We have a problem over time which is not of your making it is because of the vagaries of Parliamentary voting. I would like to end the oral questioning now. You have seen the questions, would you be kind enough to answer the remaining questions for us in writing. It is not your fault at all, but we have your other colleagues who I think wish to get home tonight. It would be best if we draw this part of the deliberations to a conclusion. You are our first witnesses and you have been enormously helpful. A number of your answers will give us some food for thought. Thank you very much indeed.

2. Memorandum from Dr Donald Lyons (MIB 989)

A CRITIQUE BASED ON THE SCOTTISH EXPERIENCE

INTRODUCTION

This document is a collection of thoughts by one Scottish Psychiatrist who has experience of operating the Act and who has given advice on the development and implementation of it. It is based on my own experiences and concerns relayed to me by others, mainly in the medical profession but also social workers, lawyers, patients, carers and voluntary organisations with whom I have been associated. I will comment mainly on provisions of the Bill regarding personal welfare and medical treatment rather than financial matters.

DEFINITION OF INCAPACITY

Section 2 defines incapacity. The definition is very similar to the test of competence in case law, notably Patient C in Broadmoor Hospital. The Scottish definition is not dissimilar to this. In Scotland, incapacity is defined as being incapable of acting or making decisions or understanding decisions or communicating

decisions or retaining the memory of decisions. On balance, I prefer the definition in the draft Bill. The main difference is the question of retention of information. It is my opinion that a person does not have to spontaneously recall all the decisions he or she makes in order to be regarded capable of making these decisions. I cannot recall the decisions I made at my last outpatient clinic but I do not think I am incapable of making these decisions. I made a written record of the decisions and I will (hopefully) agree with the written record that I made and recognise that as having been my decision at the time. I would therefore advise that, as far as memory is concerned, the definition is increased slightly. In addition to retaining information for long enough to make a decision, the person must make that decision consistently on the basis of the same information and/or agree with a record of that decision when presented with it and recognise that as being his/her wish. Otherwise, I applaud the definition of incapacity.

BEST INTERESTS

I dislike the term best interests as it sounds paternalistic. The general principles of the Scottish Act are better. The Act stipulates that any intervention must be for the benefit of the adult, must be the least restrictive in relation to the adult's freedom, stipulates that the past and present wishes of the adult must be taken into account and confers a duty to take the wishes of others into account in so far as it is reasonable and practicable to do so. The Scottish Act has a further principle that applies only to people holding certain offices under the Act to encourage the adult to use existing skills and develop new skills.

With regard to the draft Bill, in addition to substituting benefit for best interest, I applaud the duty to encourage participation under Section 4(2b).

THE GENERAL AUTHORITY

I have grave concerns about Section 6 in its entirety.

(a) *Financial Issues*

My reading of this section is that I could tell a fund holder that a person is incapable of using money to pay for certain services, use money from his account to pay for it and use money to pay for my own expenses in doing it. This, in my opinion, is a recipe for abuse and fraud. Even with a very tight Code of Practice, I would still have significant concerns that any of us might be open to being financially abused by this Section. In Scotland, a simple mechanism for withdrawal from accounts exists under the Adults with Incapacity (Scotland) Act 2000. If Granny forgets to pay her bills, I can obtain a Medical Certificate of Incapacity from her doctor, obtain a form from the Public Guardian stating what I want to use her money for and have my application countersigned by a person of standing in the community (passport signatory sort of person). Armed with this and with the approval of the Public Guardian, a fund holder is authorised to transfer money from Granny's account into a separate account operated by me. I must keep records at all times of this because the Public Guardian, who will know of all such mechanisms, can spot check at any time. The mechanism is simple and easy to operate, the only potential difficulty being finding a person to do it as it must be a relative or friend and not somebody acting in a professional capacity. In my opinion, it is an appropriate mechanism and offers the adult much more protection than Section 6 of the draft Bill would.

(b) *Medical Treatment*

I have similar concerns with regard to medical treatment but our experience in Scotland has been mixed in trying to make the Scottish Incapacity Act work. As I read the draft Bill, it would authorise reasonable medical treatment that is in the "best interests" of the person and subject to the general provisions of the best interests test. In Scotland, medical treatment always requires a Certificate of Incapacity except for emergency cases. Also, medical treatment is very broadly defined as "any procedure designed to promote or safeguard the physical or mental health of the adult". This has proved very difficult to work for many reasons. Many of us believe that the definition of medical treatment is too broad, the needs for certification should be reserved for major treatment decisions in order to achieve a balance between protecting the adult against possible assaultive treatment and allowing healthcare professionals the scope to do what is reasonable for the benefit of the person. This part of the Scottish Act is currently subject to consultation. It is my contention that basic care, known as "fundamental healthcare", should not be subject to any formal procedure under the Act. Also, acute, short term treatment that would not normally involve the signed consent of the patient, should be in this category. Obviously, anybody intervening in such a way will follow the general principles laid out in the Act.

I do recommend a degree of scrutiny for certain categories of treatment. In Scotland, there are regulations under Section 48 of the Scottish Act that prohibits some treatments and puts conditions on others. Although not written down, there is an understanding that neurosurgery for mental disorder is exempt from the Act and not permitted using this piece of legislation. The Court of Session must approve sterilisation for non physical reasons and hormonal implants to modify sexual drive. Some other treatments are made subject to a second opinion provided via the Mental Welfare Commission for Scotland. These are Electroconvulsive

Therapy, abortion, hormonal drug treatment to reduce sexual drive and any treatment that is likely to lead to sterilisation as a consequence. There was much discussion about medication for mental disorder continuing beyond three months (or probably two months now to be consistent with the new Scottish Mental Health Act). It would be impractical to insist on second opinions but there are strong anxieties about the use of medication to modify behaviour. There are numerous studies in nursing homes suggesting that medication is overused. Under the Scottish Act, treatment is carried out using a Certificate of Incapacity, often using a Treatment Plan for which a template exists in the Code of Practice and therefore documenting the need for treatment and the consultation with others including the primary carer and nearest relative.

I would predict that many organisations will express anxieties that medical treatment will be essentially unregulated by this Bill but I would encourage legislators not to go as far down as the certification/documentation road that Scotland has. I recommend that the general “best interests” test should apply to fundamental healthcare procedures and that these should include basic nutrition, hydration, skin care and integrity, oral care, elimination, eye sight, hearing, communication, mobility and simple measures to relieve pain and discomfort. It might also include general medical examination and continuation of any long term treatment to which the patient consented while capable. This might include long term treatment of diabetes, heart disease, chronic bronchitis etc. I think there is considerable merit in people with significant incapacity having a Medical Treatment Plan that is subject to annual review. This is good practice and would be cemented by being enshrined in legislation. Also, a Certificate of Incapacity should be required for single interventions that would ordinarily require the signed consent of the patient and such certificates should indicate consultation with relevant others. However, many of us believe that the Scottish Act has gone too far in subjecting all medical treatment to certification under the Act and it is being largely ignored in many areas, especially in acute care. I therefore recommend a period of time where a test of benefit/best interest is expected but where there is no need for any formal mechanism unless signed consent would be required.

This is an extremely complex area, I have no doubt that many submissions will be made regarding this and it requires careful consideration to produce workable legislation, backed up by systems to assist and monitor the use of the Act, again something that we did not do in Scotland.

(c) Powers of Attorney

I have no specific thoughts about financial issues. These would be better dealt with by people with greater knowledge. Clearly, the welfare powers might include consent to treatment. Given the uncertainty as outlined above, the Bill should be clear about the role of attorneys with regard to consent to medical treatment. This caused some confusion in Scotland where it was not clear whether a Certificate of Incapacity was required in addition to the attorneys consent. In the Code of Practice, the decision was that both certification and consent were required but some doubt has been cast on this and this is subject to consultation at present.

DEPUTIES

Again, I will mainly comment on welfare provisions. In Scotland, we have run into difficulties with “Welfare Guardians”, roughly equivalent to the Court appointed Deputies envisaged by the draft Bill. We need to decide whether the appointment of such an office is permissive or prescriptive. For example, does the best interests test apply to a decision to move a person from his or her own home into a care establishment when the person lacks the capacity to make such a decision? This has been interpreted in different ways in different parts of Scotland. Where there is a strict interpretation that this is prescriptive and that all such decisions must require a Guardian (or Deputy), this has the potential for adding to delayed discharge problems in hospital and might leave people open to a risk of harm if a decision is delayed by court process. Also, the amount of court time that could be taken up would be prohibitive. It is clearly a mechanism that could and should be used where the person resists.

In addition, there is the question of medical treatment where the person actively resists or opposes the treatment. This is unclear in Scotland but I consider that an Intervention Order is appropriate. There appears to be no equivalent procedure in the draft Bill, ie a single order to cover a single intervention for healthcare, personal welfare, finance or property. I presume that it would be the appointment of a Deputy for a short period. With regard to the powers of a Deputy, the Scottish Act and Codes of Practice are not clear as to the provision of healthcare in the face of active resistance by the patient and I recommend clarity in the draft Bill over this issue.

OTHER ISSUES RELATING TO MEDICAL CARE

Any Attorney or court appointed Deputy may have the power to consent or refuse consent to medical treatment. However, it must be clear that such a person does not have the authority to require any healthcare worker to provide any particular specified treatment.

ADVANCED DECISION TO REFUSE TREATMENT

I welcome this part of the Bill that is a helpful clarification of the law and is consistent with case law and the good practice statement on this subject from the British Medical Association. However, see the subsequent note on Mental Health Act matters.

MENTAL HEALTH ACT MATTERS

This is an interesting short clause (Section 27) and might cause some problems.

The regulations under Part 4 of the Mental Health Act include treatment for mental disorder for more than three months. My reading of the draft Bill is that it would therefore be unlawful to treat a person for mental disorder with any medication for that disorder for longer than three months. It would then appear that the correct procedure would be to treat the person under the Mental Health Act. For people in the community and in care homes, this would be inappropriate, impossible to administer and highly restrictive on peoples freedom. Also, it would result in an enormous extra burden of work for the Mental Health Act Commission who would have a duty to arrange an independent opinion.

The situation as regards Electroconvulsive Therapy is also thrown into doubt by the Bill. As I understand it, it would be unlawful to treat a person with incapacity with Electroconvulsive Therapy even if the person were not resisting the treatment. The correct procedure would be to detain the person in hospital under the Mental Health Act. In Scotland, Electroconvulsive Therapy is a regulated treatment and it is possible to treat a person who is incapable of giving consent to the treatment but not actively resisting the procedure using the Incapacity Act with similar mechanisms for an independent opinion as exists under the Mental Health Act. I have found this a useful mechanism and less restrictive on peoples freedom. The situation in the draft Bill would require detention in hospital in every case. In my opinion, that should be the situation in law at present and I strongly disagree with the NICE "Good Practice" statement in ECT which suggests that it would be appropriate to administer treatment informally with full discussion with relatives, etc. I favour the Scottish approach.

Also, as I understand the Bill, the fact that treatments regulated under Part 4 of the Mental Health Act are excluded would mean that a person could not make an Advance Statement refusing Electroconvulsive Therapy. This may be of concern to some user groups. In Scotland, we have had protracted discussions about this and the new Mental Health (Care and Treatment) Act contains provisions for a person to make an Advance Statement in respect of treatment for mental disorder but that this Statement could be overturned by a Mental Health Review Tribunal. This is an issue that would require further consideration.

Taking all the above into account, I very strongly recommend that Section 27 is dropped and replaced with a section on regulated treatments and recommend the list of treatments regulated in the Scottish Act.

COURT OF PROTECTION AND PUBLIC GUARDIAN

My general concerns about these sections relate to the investigation of the use of powers by Attorneys and Deputies. In Scotland, the Public Guardian has a duty to investigate any concerns regarding a continuing financial Power of Attorney and a local authority duty to investigate concerns over Welfare Powers of Attorney. Any person with an interest may bring such matters to the attention of these bodies. The Mental Welfare Commission also has a role with regard to welfare where there is dissatisfaction with the local authority's investigation. For Guardians (the equivalent of Deputies, I think) the Public Guardian supervises financial Powers of Attorney and the local authority supervises the use of Welfare Powers.

I have personal experience of referring matters regarding Powers of Attorney to both Public Guardian and the local authority and I find these useful mechanisms. From my reading of the Bill, I am not clear how concerns about the use of powers might be relayed to the court and also whether that mechanism is perhaps too cumbersome in the first instance and that the initial complaint or concern should be investigated by direct referral to either the Public Guardian or the local authority as is the case in Scotland. Perhaps this could be considered.

CONCLUSIONS

The draft Incapacity Bill is welcomed and has much to commend it but it is my opinion that the general authority outlined in Section 6 is far too broad and that parts of the Act dealing with medical treatment and, in particular, the interface with Mental Health Law and the lessons from the Scottish experience, need to be rethought.

I hope these thoughts are of interest to the Committee and I look forward to discussing any of these matters or any other matter that the Committee wishes to raise with me.

Please note that, although I am presently the spokesperson for the Royal College of Psychiatrists in Scotland on the Act and I may have another significant national position in relation to the Scottish Act, the opinions stated are largely my own with input and advice from others who have discussed matters relating to the Act with me. They should not be taken as an official position of any other body within Scotland.

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BIOGRAPHY OF DR DONALD LYONS

Consultant in Psychiatry of Old Age and Medical Adviser for Elderly Services for Greater Glasgow Primary Care NHS Trust.

Member of the National Implementation Steering Group for the Adults with Incapacity (Scotland) Act 2000.

Spokesperson for the Royal College of Psychiatrists on the above Act.

I am also a specialist in the administration of Electroconvulsive Therapy and a founder member of the Scottish ECT Audit Network.

I was a member of Council of Alzheimer's Scotland—Action on Dementia for 8 years and have published extensively on the Scottish Act.

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September 2003

ADDENDUM

ISSUES ON MEDICAL RESEARCH

This is a brief addendum to a report I previously submitted on the Draft Mental Incapacity Bill.

The Bill has no provision for research on people on incapacity. The ethical situation as regards research where people cannot give consent is unclear and could be helpfully clarified by legislation under this Bill. In Scotland, the Adults with Incapacity (Scotland) Act 2000 permits research under the following circumstances:

- The research must be into the incapacity (causes, care, treatment, etc).
- The research must be of real and direct benefit to the adult. If it is not of real and direct benefit to the adult, it must be likely to benefit others with the same incapacity through greater scientific understanding of the condition.
- The research project must be one that cannot be performed using people who are capable of consenting.
- There must be no or minimal foreseeable risk or discomfort from the research.
- Consent will be obtained from a Welfare Guardian or Attorney with authority to consent. Failing that, consent is obtained from the nearest relative.

The issue of consent has thrown up some issues in Scotland. For instance, a person with learning disability may not have a nearest relative available to give consent. Also, if a researcher wishes to study issues of abuse, it may be that the nearest relative is the alleged abuser and would be an inappropriate person to give consent. Under such circumstance, we have proposed that a person acting in an advocacy capacity with no interest in the research should be able to give consent on behalf of the adult. We do not as yet know whether the Scottish Executive will take this suggestion up.

I hope this is a helpful addendum to my previous submission.

3. Memorandum from The BPS Division of Clinical Psychology (Scotland) (MIB 991)

SUMMARY

1. *Background:* Highlights interest of BPS DCP (Scotland) in Bill in light of experience of Adults With Incapacity (Scotland) Act 2000 [AWI Act] and welcomes these proposals.

2. *Context—The Adults With Incapacity (Scotland) Act 2000:* Notes that there have been difficulties with the timescale of implementation. Details the main elements of AWI Act.

3. *Experiences in Implementation of the Adults With Incapacity (Scotland) Act 2000:* This emphasises the importance of the principles of AWI Act. Inconsistency in implementation is identified along with some areas of confusion, particularly in relation to the part dealing with medical treatment. Key issues from the recent consultation into this part of the Act are highlighted.

4. *Key Issues for Clinical Psychologists arising from the Adults With Incapacity (Scotland) Act 2000:* The key issue discussed is how capacity is being assessed. The complexities of such assessment are identified along with the need for specialist assessment in some circumstances. Advice is given on when a psychological assessment should be sought. The need for clearer standards in the assessment of capacity is discussed. The importance of communication is emphasised along with the importance of proactive approaches to enhancing capacity.

5. *Key Differences between the Draft Mental Incapacity Bill and the Adults With Incapacity (Scotland) Act 2000:* The requirement of a certificate of incapacity for active interventions in the AWI Act is noted as the most significant difference and the implications of this are discussed, in particular the importance of how “reasonably believes” is defined and applied. It is suggested that some form of certification should be required in some areas. The apparent greater emphasis on communication in the AWI Act is noted along with differences in the Court system. Differences in relation to dispute resolution and consent to participation in research are also identified.

6. *Lessons to be learned from the Adults With Incapacity (Scotland) Act 2000:* These identify that: the pace of implementation is crucial; there is likely to be a requirement for a huge investment in training; there is a significant need for clarity on the different levels of assessment which will be applied under the Bill; interpretation of the Bill will change over time, and that detail of the practicalities of intervention under the Bill in the codes of practice will be beneficial.

7. *Additional comments on the Draft Mental Incapacity Bill:* The importance of interpretation of the language used in the Bill is identified. It is suggested that there are benefits in Visitors from psychology and speech and language therapy being included. Concern about monitoring of abuse of the powers in the Bill is noted. The need for a substantial research programme is highlighted. Appendices are provided on assessment of capacity, “best interests”, and references.

1. BACKGROUND

(1) The BPS Division of Clinical Psychology (Scotland) has been invited to provide a response to the consultation on the above Bill, with particular reference to the lessons that can be learned so far from the implementation of the Adults With Incapacity (Scotland) Act 2000 [AWI Act].

(2) Although there are a number of teething problems with the AWI Act it has been welcomed as a significant improvement on what went on before and has clearly enhanced the rights of vulnerable adults and their carers. It is encouraging that similar safeguards are planned for individuals in England and Wales.

(3) As no formal study of the implications of AWI Act for psychologists has been undertaken, and current general research projects into the Act have not yet reported, this response is somewhat anecdotal, but reflects the experience of a number of senior practitioners in clinical practice.

2. CONTEXT—THE ADULTS WITH INCAPACITY (SCOTLAND) ACT 2000

(1) The AWI Act was the first piece of legislation introduced by the Scottish parliament.

(2) There is a perception that, with hindsight, the Act was introduced before appropriate systems were fully in place.

(a) Some parts of the Act were introduced before the Codes of Practice

(b) The planned dates for implementation of the Act were delayed

(c) Although there has been a huge investment in awareness training, the experience of this has often been that participants were left with a lot of unanswered questions about the specifics of how the AWI Act should be implemented in practice.

(3) AWI consists of 6 parts

Part 1 General principles & administrative systems

Part 2 Continuing powers of attorney (commenced 2 April 2001)

Part 3 Accounts and funds (commenced 2 April 2001)

Part 4 Management of residents' finances (originally due April 2002, commenced 2nd June 2003)

Part 5 Medical treatment and research (originally due Autumn 2001, commenced 1st July 2002)

Part 6 Intervention orders & Guardianship orders (commenced 1 April 2002)

(4) Whilst clinical psychologists may become involved in providing assessment or advice relating to all aspects of the AWI Act, the greatest involvement has related to Parts 5 and 6.

3. EXPERIENCES IN IMPLEMENTATION OF THE ADULTS WITH INCAPACITY (SCOTLAND) ACT 2000

(1) The general principles of AWI are emphasised strongly in the legislation.

All decisions made on behalf of an adult with impaired capacity must:

- benefit the adult;
- take account of the adult's wishes, if these can be ascertained;
- take account of the views of relevant others, as far as it is reasonable and practicable to do so;
- restrict the adult's freedom as little as possible while still achieving the desired benefit;
- encourage the adult to use existing skills or develop new skills.

(a) These principles have become well established with health and social work professionals and the emphasis on them is viewed very positively.

(b) There would appear to be a significant benefit in the principles of the Act being prominent in this fashion.

(2) There is a great deal of inconsistency across the country in how the AWI Act is being implemented in practice.

(a) Some clinical psychologists are now regularly being asked to provide detailed assessments of capacity by doctors in relation to medical treatment and by social workers in relation to potential applications for Guardianship or Intervention orders. Clinical psychologists in other areas working with the same client population have had no such requests.

(b) In some areas requests for assessment appear to be made whenever a Certificate of Incapacity is being considered (in some cases even when it would appear abundantly clear that the individual is incapable). Other areas refer only when complex issues are involved.

(3) It is clear in the Code of Practice to Part 5 of the AWI Act that "medical treatment" is defined as including "any procedure or treatment designed to safeguard or promote physical or mental health" and that this includes psychological treatment, however:

(a) There is confusion about the level of psychological intervention (particularly indirectly through carers) which requires certification under the Act.

(b) Due to this confusion there is little evidence of psychologists proactively seeking certification by medical practitioners for psychological interventions (and in some cases where such certification has been sought this has immediately been dealt with by the GP by them referring back to that clinical psychologist for an assessment of capacity!).

(c) The level of familiarity with the detailed requirements of the Act is in need of enhancement across a range of healthcare staff.

(4) Guardianship and Intervention orders are being increasingly used, although there is still a lot of learning to be done as to how they can be used most effectively to promote the rights and safety of individuals. There is also:

(a) some evidence of the "threat" of Guardianship being used to promote co-operation with intransigent relatives;

(b) inconsistency across local authority areas in the use of these measures.

(5) Part 5 of the AWI Act is generally recognised as requiring further revision as evidenced by the recent consultation exercise on possible revisions (responses currently being analysed). Of greatest interest to psychologists in this consultation were questions relating to:

(a) The principle of proportionality which would allow different levels of assessment to be applied which would reflect the implications of treatment and interventions of a greater or lesser gravity. We would welcome the introduction of a variable assessment procedure which would reflect the scope and degree of the intervention or treatment proposed. This could mean that referrals to

clinical psychologists would focus on cases where there was borderline capacity, conflict, other complex or complicating issues, or where a full multi-disciplinary assessment was in the person's (or public) interest.

- (b) Whether it would be possible for someone other than a registered medical practitioner to sign a certificate of incapacity. We would welcome this provided appropriate safeguards were in place in line with the variable assessment procedure above.

4. KEY ISSUES FOR CLINICAL PSYCHOLOGISTS ARISING FROM THE ADULTS WITH INCAPACITY (SCOTLAND) ACT 2000

- (1) The most significant issue is how capacity is being assessed.
 - (a) The onus of assessment of capacity falls on registered medical practitioners, many of whom have very little contact with some of the groups of vulnerable adults for whom incapacity is an issue.
 - (b) There is even evidence that specialist medical practitioners can be inconsistent in their assessment of capacity (eg Shah & Mukherjee, 2003), although there is no available research on this in the context of the AWI Act.
 - (c) Practitioners who are unfamiliar with the psychological complexities of these client groups may be unfamiliar with the implications of acquiescence, suggestibility, emotional maturity, cognitive bias, cognitive schema and communication difficulties in relation to such assessment.
 - (d) The BMA in their guidance on ethical and legal issues in Scotland (see annex 1) specifically highlight the need for referral for psychological assessment in complex cases. This is adapted from the Code of Practice for Part 5 of the Act (which in turn is derived from a paper by Clark, 2000), but with the advice that this be carried out specifically by a psychologist being added to the statement in the Codes of Practice.
- (2) There needs to be clarity on when a psychological opinion is sought.
 - (a) Clinical psychologists are a relatively scarce resource, often carrying long waiting lists. For example there are less than 40 qualified psychologists working with people with learning disabilities in Scotland. To allow a timeous assessment service it will be necessary to focus this on the individuals where such specialist assessment is most appropriate.
 - (b) As indicated above it is suggested that it would be appropriate to focus on cases where there was borderline capacity, conflict, other complex or complicating issues, or where a full multi-disciplinary assessment was in the person's (or public) interest.
- (3) Although psychologists are well placed to use their clinical skills in the assessment of capacity, it has become clear that there is a need to develop clearer standards to ensure consistency of approach.
 - (a) As each assessment of capacity has to be individualised and decision-specific it is unlikely that any single assessment package will be appropriate to assess capacity.
 - (b) However, agreement on the introduction (or development) of "standard" assessment measures is likely to be beneficial (eg Arscott et al., 1999; Grisso & Appelbaum, 1998) in so far as these can provide a consistent structure to assist clinical decision making.
 - (c) These could be enhanced by the development of assessments which are specific to particular types of decision, such as those developed by Suto et al., 2002, in relation to financial decision making and Wong et al., 2000, which focussed on capacity to decide about having a blood test.
 - (d) The creative, individualised approach to assessment of capacity for specific decision making would continue to be available as the most specialised approach to assessment.
 - (e) The provision of structured algorithms/assessment models for other professionals, such as GP's could be of benefit in guiding them through the assessment of capacity with individuals where it is not an obvious decision, and could identify cases where more specialised assessment was required.
- (4) The AWI Act is very clear in putting an emphasis on the assessor to ensure that they make every effort to enhance communication with the individual
 - (a) This requires greater use of Speech and Language Therapists, and others who may enhance communication with individuals to ensure a person centred approach.
 - (b) There is a need to produce information about medical (and social welfare and financial) interventions in ways which are accessible to people with communication difficulties.
- (5) Despite one of the key principles of the AWI Act being that of encouraging the adult to use existing skills or develop new skills there is currently little evidence of any work on the enhancement of capacity being reported. Education strategies will clearly be able to enhance the capacity of some individuals (for example, those who have recently moved out of institutions).

5. KEY DIFFERENCES BETWEEN THE DRAFT MENTAL INCAPACITY BILL AND THE ADULTS WITH INCAPACITY (SCOTLAND) ACT 2000

(1) It is encouraging that most features of the AWI Act and the Bill are very similar apart from labels and level of emphasis, however,

(2) The requirement that a certificate of incapacity be provided in relation to any active intervention under the Scottish Act is probably the most significant difference.

(a) Although there have been some practical problems in the provision of certificates of incapacity this does ensure that there is formal record in a standard format of such a decision having been taken.

(b) This has developed from the original proposals regarding certification to a position now where this certification can specify a range of elements in the treatment plan for an individual and can include fundamental healthcare procedures.

(c) The absence of such a certification in the Draft Mental Incapacity Bill does lead to concern about the process of decision making, especially where the standard of assessment is that the person “reasonably believes” that the individual lacks capacity.

(i) In this case the definition of “reasonably believes” is absolutely crucial to the equitable application of the powers under the general authority.

(ii) There is a significant risk that the quality of decision making will be a reflection of the ability of the assessor (who in many cases will be unfamiliar with the issues highlighted in 4.(1)(c) above, rather than of the capacity of the individual concerned.

(iii) Pragmatically, this may be of less significance in relation to low level interventions (and there are probably advantages in not requiring certification for these), but as interventions become more intrusive the need for standardised formal recording increases.

(iv) There is potentially a risk of individuals with “overpaternalistic” attitudes being very ready to take decisions on behalf of a person on the assumption that it must be in their best interests.

(3) There appears to be a greater emphasis on the importance of enhancing communication in the AWI. This is crucial in protecting the rights of individuals who otherwise erroneously might be deemed incapable of decision making, when the fact is that the assessor has failed to communicate effectively.

(4) The AWI has not led to the development of a specialist Court system as is proposed in the Bill. It is anticipated that this will be watched with great interest. It does appear however that the Scottish system is potentially more accessible as the Code of Practice for Part 5 states that “Anyone having an interest may apply to the Court of Session for a determination as to whether treatment should be given or not”, whereas the Draft Bill appears to be more restrictive in defining who can intervene.

(5) It is unclear how disputes in relation to decisions about medical treatment are to be resolved, whereas this is detailed very clearly within the AWI Act and associated codes. However, the role of medical visitor is also different, and again we feel this will be watched with interest as to the precise nature of the role.

(6) The AWI has a range of specific requirements in relation to research with adults who are incapable of consenting. It is not clear how this will be dealt with in relation to powers under the Bill.

6. LESSONS TO BE LEARNED FROM THE ADULTS WITH INCAPACITY (SCOTLAND) ACT 2000

(1) The pace of implementation is crucial.

(a) It is important that all of the necessary documentation and training is in place before the Bill is implemented (and the experience of Scotland is that this will take much longer than anticipated).

(2) There is likely to be a requirement for a huge investment in training.

(a) It is important that in addition to training in the general operation of the Bill there is a national programme of training in the specific application of the elements of the Bill.

(b) If this is not done it is likely that a wide range of local interpretations will develop which will inevitably lead to inequity.

(3) There is a significant need for clarity on the different levels of assessment which will be applied under the Bill.

(a) This should include the development of a range of assessment materials which will be available to decision makers to ensure consistency in applying the tests of capacity specified in the act. It is clear from the Scottish experience that these “high level” principles of assessment are not enough in themselves when it comes to making complex decisions about peoples lives.

(b) Many clinicians have highlighted a desire for clearer guidance on how to provide assessments.

(c) There should also be a clear process of assessment of capacity which highlights the situations in which specialist and/or multi-disciplinary assessment is required to ensure that the rights of an individual are protected.

- (d) The models of assessment adopted need to be reliable, valid, flexible, reasonable, practicable, defensible, principled and the minimum intervention required to make the decision.
- (e) Pragmatically, busy clinicians will benefit from having “off-the-shelf” tools which can be used to aid clinical judgement.
- (4) It is important to recognise that this is a complex area and that as practice develops so will interpretation of how the Bill is to be best applied.
- (5) The more details of practical interventions that are highlighted in the codes of practice the better.

7. ADDITIONAL COMMENTS ON THE DRAFT MENTAL INCAPACITY BILL

(1) The language used in the Bill is extremely important, and how it is interpreted will have a very significant impact on the implementation of the Bill.

- (a) It is therefore crucially important that there is clear guidance on what is meant by “Reasonably believes” as this is the foundation for much of the decision making involved in the Bill.
- (b) The other very significant term is that of “best interests”, which is defined in the Bill and described elsewhere as being a checklist. It is our belief that this would be further enhanced by incorporating the BMA guidance on “best interest” (see annex 2) with the addition of a statement indicating the need to consider the psychological well-being of the individual.

(2) The Bill specifies a role for Medical Visitors and General Visitors, both of which are welcomed. However consideration should be given to introducing other specialist visitors, specifically Clinical Psychologists (who are best placed to provide a specialised assessment of capacity in relation to both medical, social and many communication issues) and Speech and Language Therapists (who are best placed to provide specialised assessments in particular areas of communication). Both of these categories of professional visitors could operate in the same fashion as a Medical Visitor within their respective areas of expertise.

(3) In considering decision specific capacity it is important to consider the level of capacity which is required for different decisions and whether this is higher than that for the general population (see Murphy & Clare, 2003).

(4) The effectiveness of the Bill in achieving its aims will to some extent depend on how far professionals and carers who are involved in the care of vulnerable people are prepared to identify situations where the general authority is being used inappropriately. It is important in situations where significant lifestyle and medical decisions are being taken on behalf of another person that there is clear monitoring of this in place. This should not only be in terms of abuse and exploitation, but also in relation to overpaternalistic and overly risk-averse attitudes as this can also be damaging to the individual.

(5) There is a clear need for a substantial research programme to accompany the development of this Bill to ensure that it achieves its aims.

August 2003

Annex 1

BMA website—

Medical treatment for adults with incapacity: guidance on ethical & medic-legal issues in Scotland—2nd edition October 2002

“Assessment of capacity

Capacity is assessed in relation to a particular decision that needs to be made. An assessment of capacity is not based on the test “would a rational person decide as this person has decided?” Rather the thought processes behind the decision are relevant to the question of capacity. . . In cases where patients have borderline or fluctuating capacity, it can be difficult to assess whether the individual can make valid decisions on very serious issues. The BMA has published detailed practical advice about assessing capacity. In many cases there will, of course, be no doubt about a person’s capacity. **Where there is doubt, a comprehensive psychological investigation may be needed, which would seek to determine whether the adult**

- is capable of making a choice;
- understands the nature of what is being asked;
- understands why a choice is needed;
- has memory abilities that allow the retention of information;
- is aware of any alternatives;
- has knowledge of the risks and benefits involved;
- is aware of the decision’s personal relevance to him or herself;
- is aware of his or her right to refuse, as well as the consequences of refusal;
- is aware of how to refuse;

- is capable of communicating his or her choice;
- has ever expressed wishes relevant to the issue when greater capacity existed; and
- is expressing views consistent with previously preferred moral, cultural, family, and experiential background.

A patient's abilities can fluctuate because of a range of factors, including medical condition, medication, time of day or mood. Doctors have a general ethical duty to enhance capacity when it is possible to do so, and should seek to engage patients in decision making when they are best able to participate.

Doctors constantly assess whether patients have the capacity to make the decision they are faced with. Mental abilities can be influenced by both medical and psychiatric conditions. Any doctor should, however, be able to take a psychiatric history and to conduct a basic mental state examination in order to define straightforward abnormalities irrespective of their cause. Many people can be assessed by their own GP. Indeed a close, long-term acquaintance with the person being assessed may be an asset, particularly if the person is more relaxed with a familiar doctor. **Where the person's capacity is borderline, however, or the treating doctor does not feel able to make an objective assessment, specialist advice should be sought.**"

[bold type for emphasis—not in original].

Annex 2

BMA CONSENT TOOL KIT SECOND EDITION FEBRUARY 2003

Card 8—Determining "best interests"

A number of factors should be addressed including:

- The patient's own wishes and values (where these can be ascertained), including any advance statement;
- Clinical judgement about the effectiveness of the proposed treatment, particularly in relation to other options;
- Where there is more than one option, which option is least restrictive of the patient's future choices;
- The likelihood and extent of any degree of improvement in the patient's condition if treatment is provided;
- The views of the parents, if the patient is a child;
- The views of people close to the patient, especially close relatives, partners, carers or proxy decision makers about what the patient is likely to see as beneficial; and
- Any knowledge of the patient's religious, cultural and other non-medical views that might have an impact on the patient's wishes.

We would suggest that a statement relating to the impact of the proposed intervention on the psychological well-being of the individual should be added to this list.

Annex 3

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Witnesses: **Professor Tom McMillan**, Chair in Clinical Neuropsychology, Glasgow University, **Mr Mark Ramm**, Director of Clinical Forensic Psychology, Orchard Clinic, Edinburgh, **Dr Keith Bowden**, Consultant Clinical Psychologist, Forth Valley Primary Care NHS Trust, and **Dr Donald Lyons**, Consultant in Psychiatry of Old Age and Medical Adviser for Elderly Services for Greater Glasgow Primary Care NHS Trust, examined.

Q49 Chairman: I believe you were in the audience when we started. May I welcome you. I do apologise about the timing, you realise it was out of our hands, it was what was happening in both chambers. If you would like to introduce yourselves, and, if you wish, make a short statement then we will proceed to questioning.

Dr Lyons: We have decided we will not make statements, I do not think we have anything to add to the statement that Mr Ward made. We would rather answer the questions that the ladies and gentlemen would like to ask us. I will introduce myself and then I will ask my colleagues to introduce themselves. My name is Donald Lyons, I am a consultant psychiatrist. I specialise in the care of people with dementia. I have been the spokesperson for the Scottish Division of the Royal College of Psychiatrists on the Adults with Incapacity Act in Scotland and a member of the National Steering Group for implementing the Act.

Dr Bowden: I am Keith Bowden, I am a Consultant Clinical Psychologist with Forth Valley Primary Care NHS Trust. I specialise in working with people with learning disabilities.

Professor McMillan: I am Tom McMillan, I am a Professor of Clinical Neuropsychology at the University of Glasgow. My areas of interest are in part brain injury and the rehabilitation of brain injury. I am seconded two days a week to the Glasgow Health Board where I advise them on the development of services for brain injury rehabilitation in the Glasgow area.

Mr Ramm: My name is Mark Ramm, I am a Consultant Clinical Psychologist at the Orchard Clinic in Edinburgh, which is a hospital for mentally disordered offenders who are the detained under the Mental Health Act. I am also the British Psychological Society's representative on the Reference Group in Scotland which is looking at the implementation of our recent new Mental Health Bill.

Q50 Chairman: I would like to ask the first question, you will find these questions somewhat familiar, what advantages are there in requiring evidence of a defined mental disorder as a diagnostic threshold above and beyond a person's capacity? Is it important to maintain consistency in definitions between Mental Health and the Mental Incapacity legislation?

Dr Lyons: As you will have heard from Mr Ward the definition of mental disorder as contained in the Adult Incapacity Act is exactly the same as the definition of the mental disorder contained in the Mental Health Act, and that until recently has been "mental disorder" or "mental handicap" however

caused or manifest. This is a wide-ranging definition of mental disorder. There was a lot of discussion leading up to the new Mental Health Act as to whether the definition of mental disorder legally should be narrowed and the answer eventually was no it should not. It remains wide. As with the Mental Health Act, the Incapacity Act has the additional test of capacity in that the adult must be incapable of acting or making decisions or communicating decisions or understanding decisions or retaining the memory of decisions. That is the test. Many people with mental disorder will not pass that test of incapacity and there is a grave, grave danger that we must all guard against that is written in great big letters "do you not assume an incapacity because a person happens to have a mental disorder". Concentrating on whether the person does or does not have a mental disorder is maybe the wrong way to look at it. There has to be something causing the incapacity, mental disorder is one, an inability to communicate is the other. The critical bit is the test of capacity, and that is what we must concentrate on.

Q51 Chairman: Is that the same point as the assumption in our draft Bill, there is capacity until proved otherwise?

Dr Lyons: That is a clear assumption in general.

Q52 Chairman: Do your colleagues wish to comment on that first question?

Dr Bowden: The importance of the functional test of capacity cannot be over-emphasised. It is very important in the Scottish Act that it is about decision-specific capacity. I think there is a danger if we start using terms like "incapacitated adults". We need to be very careful that we do not move into a situation where we are assuming people have or do not have capacity per se. It is important that it is about specific decisions, and that may be about specific decisions at different times in a person's life. It may be that at one stage in a person's life they are able to make that decision and at another time, perhaps because of their emotional state or their other circumstances, they may not be able to make that decision at that time. It is important that the legislation is robust enough to deal with that situation and to identify that.

Q53 Mrs Browning: In practical terms how do you deal with people whose conditions means they demonstrate variable capacity as a result? If I can give you a couple of examples: in the case of people with autism, even people high-functioning autism, their ability to conceptualise something is pretty limited. If you give them choices, "Would you like

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to do A or B?", and if that is not within the ambit of their own personal experience, they would have huge difficulties. They may even make a choice that would be totally inappropriate purely because they have not been able to conceptualise it. There are practical ways of going through that, if you were saying, "Do you want to go and live in A or live in B?", you overcome it by taking them to A or B rather than sitting around in a case conference. For example, with schizophrenia where people may be going through an episode at any given point in time but later on may be in a recovery situation. How in practical terms do you deal with those conditions?

Dr Bowden: I think the principle of minimum intervention is one of the important elements with the Act—and I am speaking as a clinician—that we should be intervening at the minimum level to assist that decision-making. An important emphasis in the Scottish Act is that the onus of communication is placed on the health professional, that we should be seeking to communicate with the individual in the most effective way to ensure that their contribution to the decision-making process is as much as it should be. With a person with Asperger's, for example, it is about specific time-related decision making and it may be that at one point we do need to implement the certificate of incapacity and take that decision on behalf of the individual whilst acknowledging as much as we can about what their desire is. On another occasion when we have been better at communicating or finding a way to assist that person to make that decision then they have the capacity to make that decision and we should follow their decision.

Q54 Lord Pearson of Rannoch : Would you accept that, although mental health as a category can move forwards and backwards in various degrees over time, there are some people who are so mentally handicapped, with such severe learning difficulties and intellectual impairment, however you want to compromise, they will never be able to make decisions for themselves or something of that kind. Would you accept there are people in that category?

Mr Ramm: There are many situations where it is very easy to make the decision they have a lack of capacity. I think that the legislation works very well in relation to be able to deal with their needs and the needs of their carers. What is often more problematic is there can be an assumption by many that that is always an easy decision and there are many, many situations where deciding whether somebody has capacity or they do not is very difficult. There are many borderline cases, as has been observed. There are cases where a person's level of capacity to make decisions for themselves will change over time and there are many cases where a person will be capable of making a decision for themselves in one area, for example financial affairs, and not in another. Because of these more complicated cases what is required typically for clinicians and the individuals involved in the

operation of the Act are very clear guidelines and very clear processes on which to make these decisions.

Chairman: We will to break for ten minutes. There is a vote in the Lords.

The Committee suspended for a division.

Chairman: We can now proceed.

Q55 Baroness McIntosh of Hudnall: Sorry about the interruptions. Just picking up from the discussion that was going on before we disappeared, on the question of how you define incapacity and in what situations and so on, in our draft Bill there is clause 2.1 which lists some ways of testing whether a person is unable to make decisions. Is it your view that this is a helpful list? Is it comprehensive? Will it assist you as clinicians in making the decisions that you have to make?

Dr Bowden: I think there is a similar difficulty with this list as with the adults in the Incapacity Act in terms of the specificity that is involved in this estimate. I think it operates very well in terms of the straightforward decisions where it is very clear that someone has capacity about a decision or indeed where it is very clear that someone does not have incapacity about that decision, but in terms of the more complex decision-making that I as a psychologist would be involved in assessing, apart from giving me a general structure under which to operate, it does not really give me the gold standard of assessment that I would look for to give advice as to what that decision should be.

Q56 Baroness McIntosh of Hudnall: Can you say what is missing from it, is there an obvious thing that is missing from it, or is there something in your legislation that you would want to see included?

Dr Bowden: I think it is about the Codes of Practice and the level of detail that comes in in the Codes of Practice. I think the high level operation of this is fine, but it is about how that is applied in practice and I think our experience is that different practitioners are interpreting this sort of high level statement differently in the way they apply it in practice, so the key is about further definition and detail at the Codes of Practice level.

Dr Lyons: May I make a quick point about that. Medical practitioners will like this definition and I know where it comes from because it is almost a direct lift from the Broadmoor Hospital case. For that reason, because it pertains to a judgment of medical treatment, doctors will quite like and will operate this quite well. I actually quite like it. I have to say I probably like it more than I like the Scottish definition. The thing that is missing from this definition is that the person may be able to make a decision but may not be able to secure his interests by acting on this decision. Mr Ward mentioned that earlier and that is something to think about. That is in the Scottish definition, it is not in this. The other comment I would make about this is not so much in 2.1 it is more in 2.4. As I specialist this particularly interests me and it concerns the question of memory. The draft Bill is

quite right to say that a person shall not be regarded as incapable because he or she does not spontaneously remember the decisions. I had an outpatient clinic on Monday and I do not remember the decisions that I made there, but I wrote them down and with a bit of luck I will go back and be able to read my writing and I will agree with what it was. That is the key, that there has got to be some degree of consistency to the decision-making. The person must either make the same decision consistently given the same information, and/or when presented with a record of that decision they have to recognise that decision as their will. That is the issue of memory decision-making to my mind.

Professor McMillan: If I could add to that. The point seems to me to be the person has to retain information long enough to be able to make the decision because you can then return to the issue and check whether the decision is consistent. So it is not being able to remember the information, it is remembering long enough to make the decision. There are quite a few patient groups where that will be an issue. They can retain information but only for a short period of time.

Q57 Chairman: How do you handle the situation where a person retains the information and they welcome the decision and then they forget all about it and you come back to implementing the decision and they say, "This is all wrong I do not want to do this." What happens then? Is that person not capable?

Dr Lyons: That person is not capable if there is no consistency to that person's decision-making. My opinion then is that that person is not capable.

Dr Bowden: Unless they are able to give reasons for that change of decision.

Lord Rix: Surely, yes, that must be right.

Q58 Stephen Hesford: Just on the back of that answer, which I must say I personally found very helpful, can I just ask the panel having practised the Scottish version and having look at our version in simple yes or no terms which would you rather practise under?

Dr Lyons: Shall we take a vote chaps? Ring the division bell at this point!

Mr Ramm: Speaking personally there is no doubt in my mind that I would much rather work under the Scottish Act. I think there are advantages in several areas. We were hearing before about the general principles. I think they are a very important aspect of the legislation and they are very, very helpful for clinicians and for everybody in terms of interpreting how it should be applied and what they should be doing. I think one of the other advantages of the Scottish legislation at present is the issue of granting certificates of incapacity. There is something important, I believe, about there being something within the system that allows a more careful analysis or assessment for issues which have a higher importance or threshold, because there is a threshold issue. Obviously in practice one would not want to make it too difficult

for a GP and a family to care for, say, an elderly relative in terms of administering their finances. One would not want to make that too difficult for them to organise between them, but if the relatives for example were to decide that they were going to sell the relative's house, at that point the whole issue would deserve a much more careful assessment of the person's capacity in relation to deciding that issue. The certificate in Scotland makes it much clearer when there should be a multi-disciplinary assessment and the nature perhaps of this assessment.

Q59 Stephen Hesford: Thank you. Do you all share this view?

Dr Lyons: Let us be clear on the question that is being asked here. Is the question that is being asked purely about the definition of "capacity" or about the Scottish Act and the drafting of this Bill in general?

Q60 Stephen Hesford: To save time it was the global balance issue. For my part I could not see that you could split it up, so it is the whole thing really.

Dr Lyons: You can split it up. Personally I would not want to work under this Bill. If this became an Act I would not want to work under it; I would have grave reservations about it.

Q61 Stephen Hesford: As a practitioner?

Dr Lyons: But I do like the definition of "incapacity" in the Act with the provisos that I have laid down.

Q62 Chairman: Your colleagues agree?

Dr Bowden: Yes, on the Act as a whole as it stands I very much prefer the Scottish version. I think there are particular issues around general authority to treat. In terms of the specific aspect of definition it does come down to the detail about how that is operated in practice.

Q63 Lord Rix: I am coming from Mencap's point of view. We find that the title of the Bill and to a certain extent the Scottish Bill is slightly demeaning and slightly threatening. "Incapacity" indicates something whereas capacity is more positive. I notice in Canada in the equivalent Bill, which comes back to what you were saying just now, is called Substitute Decision and Advocacy Act, which is what you were saying a moment ago. I find—and I know this is Mencap's view, but it is my personal view as well—the use of the word "mental" and "incapacity" has a threatening tone to it and covers a whole belief in the Bill. You are looking always on the negative side right throughout whereas if it is a more positive title you can have a more positive and friendly view of the Bill.

Professor McMillan: It is not clear to me there is an advantage in having the word "mental" in the title of this Act.

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Dr Lyons: I agree.

Dr Bowden: Yes.

Dr Lyons: Yes, and I like the “Substitute Decision Bill”. It is an excellent idea.

Q64 Huw Irranca-Davies: To return to 2(1) and the definition of “mental incapacity” your comments contrasted this aspect of the Code of Practice, and your position is that you feel quite content working what is laid down here with your provisos. In the way that legislation is drafted do you feel there is any suitable combination that would refer to Codes of Practice that could flesh out and add more detail and so on. Do you feel that this should be on the face of our Bill?

Dr Bowden: I think one example might be in terms of the use of the term “unless all practicable steps have been taken.” What in fact does that mean? For a GP who has perhaps seven minutes to see an individual, what practicable steps has that GP to take in order to make a decision about capacity? Under the Scottish Act that GP should be ensuring that he or she is communicating well with the individual, that he is taking the wishes of the individual into account, that he is consulting with relevant others including the family and other carers who may be involved with that individual. How far that actually operates in practice is unclear. Our suspicion would be that some GPs, or indeed other medical practitioners, do so very thoroughly following all of the principles of the Act. Other GPs will take the view that it is not reasonable or practicable (which is the term in the Scottish Act) for them to spend all of that time to do it. They know their patients and will say, “I have made my decision under the principles of the Act”, whereas I, as someone involved in supporting that individual, would argue to the contrary, so detail about what “practicable” means in the Code of Practice would be of great benefit.

Q65 Huw Irranca-Davies: On the face of the Bill?

Dr Bowden: I think Codes of Practice would probably be where it would sit better.

Dr Lyons: In all the Codes of Practice it has got a very clear step-by-step guide as to the best ways and the best environments to assess somebody’s capacity—making sure we do it in an environment familiar with the person, supportive for them, comfortable for them and in a way that is best for them.

The Committee suspended for a division.

Chairman: I am informed that we are quorate. Jill?

Q66 Baroness Knight of Collingtree: I am going to try and roll a few questions up. I think the first one I want to ask is in what ways would the inclusion or perhaps a more explicit emphasis of these general principles in our draft Bill actually assist practitioners working with people with incapacity? We have heard a good deal which has helped us very much on this particular principle, but I thought I should give you the opportunity to answer that question. I want to go on to say could

you tell us the relative merits of the concept of “benefit” and “best interests” in this particular context. Is the proposed “best interest” check-list likely to be useful to clinicians working with people with incapacity? Would it, for instance, enable a balance to be struck between supporting the autonomy of the person with incapacity and providing them with protection? Finally I would like to say I was rather alarmed to hear Dr Lyons say that if a person was not consistent then he was incapable.

Dr Bowden: Touché.

Q67 Baroness Knight of Collingtree: I must admit that rather alarmed me. In the sphere of what we are talking about I was particularly thinking of someone who had one of those mental illnesses which they come and if the person takes their medication they go, so that you could be inconsistent at one moment and fairly consistent the next. I was a little bit concerned about that. I am sorry to have rolled all those up but there they are.

Dr Lyons: Can I take that last point firstly. I said that was in relation to a very specific instance given where somebody makes the decision and then given the same information says, “No, I do not want that at all.” If that is done within a very short space of time you have doubts about that person’s capacity. Somebody’s capacity may fluctuate, somebody may be incapable for a short time. That is a very important point to make—the capacity can either be temporary or permanent. There may be instances where you have to temporarily intervene to help somebody when they are incapable for a short period of time until they regain capacity, and then they are capable.

Q68 Baroness Knight of Collingtree: So there can be a time limit on incapacity?

Dr Lyons: Absolutely, absolutely, yes. It is not an all and nothing, it is not start and then continue. You only intervene using the Scottish Act for example for as long as that person is incapable and when that person retains capacity the Act no longer applies to them.

Q69 Baroness Knight of Collingtree: Do you think that would also apply to our draft Bill?

Dr Lyons: It might be worth making it a little bit clearer in the draft Bill that the capacity can either be temporary or permanent. Not having the Scottish Act in front of me I cannot remember but I think the Scottish Act says that; the Codes of Practice definitely do. If I come back to the other question you rolled up and particularly if I compare the best interests test within the draft Bill with the five principles in the Scottish Act, the very first thing the Scottish Act says is that there shall be no intervention in the affairs of an adult with incapacity unless that intervention will benefit the adult. That is the very first thing the Act says and that really sets the tone for the whole Act. I do not see that tone in this Bill.

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Q70 Baroness Knight of Collingtree: The trouble with that is that people's opinion of what is beneficial for a certain person can vary greatly.

Dr Lyons: And I would argue that the benefit has to be evidence based. You have to be able to say at the outset, "Is what I am going to do likely to be of benefit to this person?" What is the evidence for that? I say that particularly with regard to medical treatment because that is my forte. If I can give you an example of that. One of the concerns that you will hear in this Committee is the use of sedative medication in people with dementia in nursing homes. What benefit is that having for that person? One might come along and judge it is in their best interests to be sedated, but where is the evidence base for the benefit of that intervention? And in Scotland that is what you would have to test it against, and that is why I like the idea of "benefit", which I think is a more defined concept than "best interests", which I do not think is defined even in this.

Q71 Baroness Knight of Collingtree: But might it not be? Certainly there have been instances of this where some doctors have felt it was in a person's best interest to end their life.

Dr Lyons: I do not think any doctor in this country thinks it is the best interests of somebody to take active steps to end their life, no. We will probably go on to talk about issues to do with advance statements and withdrawing and withholding treatment. I want to say one thing on what Mr Ward said, for every one *Tony Bland* case, for every one *Law Hospital* case, there are hundreds of thousands of people with advanced cancer, with advanced dementia, with advanced stroke disease and we have to make decisions on whether or not to intervene day in day out. The *Law Hospital* case and the *Tony Bland* case were high profile, but those are not cases that should dominate our thinking in this area.

Q72 Chairman: Almost all the cases you have just mentioned would have capacity. Is it right that if you have got advanced cancer you still have capacity.

Dr Lyons: No, in advanced cancer you may have brain secondaries, you may have lost capacity, if you have advanced dementia you may very well have lost capacity.

Dr Bowden: A person with a learning disability and cancer.

Q73 Lord Rix: There is a question here which flows on from that. To what extent can scrutiny by research ethics committees provide the necessary safeguards to protect people from exploitation for the purposes of research? I personally do not like the word "research" at all because I think, like "mental incapacity", it has a certain threat behind it, so I would rather they found some other word, like "treatment".

Dr Lyons: May I outline first of all what the Scottish Act says about research and my colleagues may like to come in, as I am not a researcher by

trade. The Scottish Act does permit research involving people with incapacity under certain restrictions. It must be research into the care, treatment, causes, et cetera, of the incapacity itself. It must be research that cannot be performed in people who are capable. It says in the Act that the research must be likely to be of real and direct benefit to the adult. We all know that if what we were going to do was going to be of real and direct benefit, we would be doing it, we would not be researching it. That is not what research is about. The Act has to say that because of the general principle in the Scottish Act about benefit. Then it gives you a clause which says if it is not going to benefit the adult it must be likely, through greater understanding of the condition, to provide real and direct benefit to others who suffer incapacity. It is then up to the research ethics committee to decide what that link might be. Then it must involve no or minimal foreseeable risk or discomfort and must have a consent from a proxy with authority to give consent, or failing that the nearest relative, and that has caused some difficulty in undertaking research where there may not be a nearest relative or where the research may be into actions involving the nearest relative, perhaps even allegations of potential abuse where the nearest relative is not the appropriate person to get consent from. That has been highlighted as an issue for the Scottish Act. Maybe colleagues with research backgrounds might like to add to that.

Professor McMillan: I agree with what you say. The other category that I would mention is of course acute cases which may be presenting at accident and emergency where of course you cannot get consent, but where we do want to improve care and treatment. We want to understand about symptom persistence and psychological issues in these cases. At the present time it is quite difficult to do research in that category of case, although I note there is a comment in the draft Bill about the case.

Dr Bowden: One further point on it. The Scottish Act as it stands, however, can act as a disincentive to local research which may be small pilot projects that would lead to a more established research programme because of the fact that that then has to go to the national ethics committee for approval. It can discourage the low level of research and we need to be careful about that.

Q74 Laura Moffatt: Gentlemen, I need to return to the issue of benefit. You heard the question that I asked previous witnesses but of course I cannot ask that because you have not got withdrawal of treatment as part of the Scottish Act so therefore my question is going to change. Firstly, as practitioners are you glad about that? Are you glad that you do not have to include that decision-making as part of the Act? Secondly, I was so pleased to hear you say, Dr Lyons, that you should not really concentrate on the high profile cases because as a nurse for 25 years I know very many more decisions are having to be made that are not high profile and it is going on from day-to-day and

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it is quite difficult. Could you first of all tell me if there are any advantages to decoupling that issue? When you see the weight of evidence that has come to the Committee on that particular subject then I am beginning to see it too, to be honest.

Dr Lyons: I absolutely understand the anxieties people have about this whole question of withdrawing or withholding life saving treatment. I have a couple of things to say about that. First of all, can I be clear with the Committee that in the eyes of the Ethical Department of the British Medical Association there is no difference legally and ethically between withdrawing treatment and withholding treatment in the first place. I know it might look different and it feels different when you are doing it, but the end result in either case is the person is going to die.

Q75 Laura Moffatt: Is that a benefit though?

Dr Lyons: Mr Ward said—and I completely agree with him—is it the intervention you have to decide on, not the non-intervention, okay, so if I am in a situation where a person has lost the ability to eat and drink and lost the ability to swallow, has an advanced illness, an advanced degree of dementia, I have to make a decision as to whether it is going to benefit that person to intervene. That is the decision I have to make. I do not decide it is going to benefit them if I do not intervene, I say it is going to benefit them if I intervene. That is the test. That is where it goes back to the evidence because the evidence base in the population that I deal with is that if you do try and intervene a) it does not benefit and b) using an artificial feeding apparatus causes distress to the person, it is uncomfortable for them, and does not prolong that person's life. That is the evidence and that is what I mean by evidence of benefit.

Q76 Laura Moffatt: I hear absolutely what you say but you have almost persuaded me that “best interest” is the best wording here then.

Dr Lyons: I disagree. I think the evidence-based test of benefit is the best way to look at it.

Professor McMillan: Could I just raise a little bit of a flag for the high profile cases not because they are high profile but because the category of case that we are talking about here. In the *Law Hospital* case and *Tony Bland* case we are talking about people with severe physical incapacity and in those cases extremely severe mental incapacity. I would like to emphasise some of the points Mr Ward made. There is an important issue in terms of having robust assessment where there is any doubt whatsoever that the person is unable to communicate and where essentially you may have somebody who is locked in but who has been adequately assessed, and it may be felt that the decision is that feeding intervention should be withdrawn. I want to raise a little flag for those cases where there is a communication difficulty and serious physical handicap.

Q77 Baroness Fookes: I cannot myself see the difference between “best interest” and “benefit” taken at face value. Is the problem for you that “benefit” is a more modern term in relation to the legislation and “best interest” carries, what shall we say, a history, it carries baggage?

Professor McMillan: Can I make a comment here. I liked Mr Ward's hierarchy where he had best interest at the bottom because the other steps you go through are evidence based and I think that is the crucial element. You are looking at evidence and by the time you get to best interest you are more concerned with opinion.

Q78 Baroness Fookes: But why should you not look at evidence or tie it in with best interest?

Professor McMillan: It may be an issue to do with semantics which I think somebody raised earlier on, but with benefit you are looking at something which you assume is going to improve the lot of the person and there is specific evidence for that.

Q79 Baroness McIntosh of Hudnall: Can I just pin this one down because this is a really tricky bit of ethical unpacking that we are doing here. I think, Dr Lyons, you said earlier on that there would be no doctor in this country—and I am not quoting you but this is what I heard—who would see being dead as a benefit or dying as a benefit.

Dr Lyons: I think you are misquoting me.

Q80 Baroness McIntosh of Hudnall: If I am misquoting you then please reply.

Dr Lyons: I said there was no doctor who would act to end somebody's life.

Q81 Baroness McIntosh of Hudnall: Act to end somebody's life, that is fine, because that sets the context for what I wanted to ask you. It appears to me that underlying a lot of what you are saying about this particular issue is a general principle, not one of these general principles, a general principle that being alive is on the whole better than being dead. I am really not being flippant, I think that does seem to me to be an underpinning principle to what are you saying, which makes it difficult to understand where issues about best interests or benefit, however you want to describe it, fit into the language of decision-making if the general principle is indeed that being alive is better than being dead because that would lead to an assumption that anything—I know this is not how doctors and medical people proceed, I know the complexity of the argument—that prolonged life was preferable to something that did not. I think we need to understand what the governing principles are here.

Professor McMillan: Is there not an issue of futility treatment and because the treatment is futile by definition of futility it is not going to accord benefit?

Dr Lyons: I can give you a quotation, I think I am quoting correctly: “To attempt to preserve a patients's life at all costs may not be fully respectful

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of the patient. You must approach end of life decisions with a healthy realism". That was Pope John Paul II.

Q82 Baroness McIntosh of Hudnall: As it happens that is a view that I share. What I am trying to understand is the tension that seems to me to be bedevilling the question of interest and benefit round the issue of withdrawal of treatment between the benefit of being alive and the benefit of not being alive, and that in the end is what it boils down to. I think that what you have just said clearly indicates that there are circumstances in which not being alive is preferable to being alive.

Dr Lyons: Can I put it another way, am I intervening to prolong somebody's life or am I intervening to prolong somebody's death. Am I prolonging the process of dying? Am I helping that person? I have to make that decision day in and day out with people with advanced dementia. I follow very clear principles laid down by the British Medical Association in how I do that and I consult widely over that. That does not involve the Adults with Incapacity Act although the general principles of the Act do guide my decision-making. My decision-making would have been within those principles.

Baroness McIntosh of Hudnall: It might be worth our while to consider what extent it is necessary to make explicit what you just said because the difference between prolonging somebody's life and somebody's death is very, very critical but it does not appear anywhere.

Q83 Lord Rix: Would that not be for guidelines rather than the Bill?

Dr Lyons: May I make a recommendation, my recommendation is that you do not write it explicitly into the Act, that is not what the Act is about. What is happening with this discussion is this discussion has been hijacked by that issue, the way that we almost got hijacked in the Scottish Act with that issue, so we left it out and that allowed us to concentrate on using the Act for people's benefit and leaving these difficult decisions to good practice guidelines.

Q84 Chairman: Did you have a draft or did your Parliament go straight to the Bill? Did you have a draft Bill and then have consultation or did you go straight to the Bill?

Dr Lyons: There was actually a lot of consultation before the draft Bill in the first place.

Q85 Chairman: So it was a draft Bill, was it?

Dr Lyons: Yes, but there was a draft Bill that came out of the Scottish Law Commission's original report and the document *Making the Right Moves* which it was eventually called.

Q86 Chairman: Were the draft Codes of Practice circulated widely for consultation?

Dr Lyons: Yes, and we all commented on them, ripped them to bits and they went away and thought again. I would say that the Code of

Practice for medical treatment in particular in the Scottish Act has its problems. We have difficulty—and there are one or two questions in here about it—because the definition of "medical treatment" under the Scottish Act is, in my personal opinion, too broad. It is defined as "any health care procedure designed to promote or safeguard the physical or mental health of the adult", which is far too broad and it is not what the Act should be concentrating on for medical treatment which is potentially contentious longer term treatment and the acute treatments that would ordinarily require a person's written consent, so I think there is a judgment to be made there. The other big difficulty with medical treatment that this Bill has is it does not close the *Bournewood* gap. I am sure you are familiar with the *Bournewood* case. This Act excludes those covered by Part IV of the Mental Health Act. That excludes treatment for mental disorders beyond three months so if somebody is incapable of giving consent to this order you could not give them treatment for that if this Bill became an Act.

Q87 Chairman: This is the draft Bill?

Dr Lyons: You would have to use the Mental Health Act so all these people would be subject to the Mental Health Act and they would all need a second opinion from the Mental Health Act Commission and you would gum the entire system up and it would not work. We were close to doing that in Scotland before we drew the Scottish Executive's attention to that so I think it is only fair to draw that to your attention as well.

Dr Bowden: I think a related point is about assessment of capacity generally across the Act. We need to look at the appropriate level and intensity of assessment of capacity really on a principle of proportionality. For minor or relatively insignificant decisions I think you are perhaps moving to the general authority to treat, and general authority is potentially there. Perhaps we have gone too far in requiring certification of Part 5 under the Scottish Act but as a psychologist I would say that where it comes to complex decision making it is crucial that a psychological opinion is coming in there in contentious and difficult cases and indeed also a speech and language therapy opinion because of the particular communication issues that can come in, and I think guidance looking at that proportionality of assessment and using the appropriate specialists to carry out these assessments and not placing that on general medical practitioners or indeed under the general authority (Jean next door) is very important.

Q88 Baroness Fookes: As you obviously attach great importance to the codes, would it be useful for us to have a copy of these codes perhaps with a critique where you feel that they may fall short or could be improved?

Dr Lyons: The Codes of Practice are certainly available on the web site on the Scottish Act. On the critique especially on the medical Code of Practice there is a consultation process at the

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moment and the responses to that will be analysed by the Central Research Unit. I am doing some research on the use of Part 5 with the University of Stirling. I think it is very important that when those reports are analysed and that research is available then we do our best to make it available to this Committee.

Q89 Baroness Fookes: And the timescale?

Dr Lyons: For the analysis of the responses it should be pretty soon.

Q90 Baroness Fookes: In time for us?

Dr Lyons: What is your timescale?

Q91 Chairman: We have to finish all our deliberations by the end of November.

Dr Lyons: I would be confident that the responses will be analysed before then.

Mr Ramm: I think there are some similar discussions amongst clinical psychologists about their views in relation to the Act as well. You have to bear in mind that even for Scotland the ramifications and implications of the legislation are still only just being worked through, so it is still very new to us.

Chairman: Sure. Thank you very much indeed. You have had the questions, we have not reached them all. If there are any questions there that you would particularly like to answer in writing that would be very helpful to us. I apologise again for all the disturbances, which were due to votes in the House of Lords mainly. Thank you very much, it has been very helpful.

Tuesday 16 September 2003

Members present:

Barker, B.
Carter, L. (Chairman)
Fookes, B.
Knight of Collingtree, B.
McIntosh of Hudnall, B.
Pearson of Rannoch, L.
Rix, L.

Mr Paul Burstow
Jim Dowd
Mrs Joan Humble
Huw Irranca-Davies
Laura Moffatt

4. Memorandum from the Making Decisions Alliance (MIB 950)

1. SUMMARY MDA RESPONSE TO THE DRAFT MENTAL INCAPACITY BILL

1.1 The Making Decisions Alliance (MDA) is a consortium of 28 organisations and groups working with people who may have difficulty making or communicating decisions (see Annex 6.1, for our full membership). Our two main aims are:

- To lobby the Government to introduce mental capacity legislation in the Queen's Speech 2003.
- To increase awareness of the need for new legislation.

1.2 The MDA is delighted that the Government has published a Mental Incapacity Bill for consultation. After 14 years of Government consultation and the publication of four reports and a draft Bill from the Law Commission, we are very pleased that there are now definite plans to develop a legal framework for decision-making for people who may have difficulties making decisions for themselves. For too long, this has been a fundamental gap in the law.

1.3 The MDA believes that the current law does not provide sufficient protection for those who lack capacity or those who look after them. Currently, the law is confusing and fragmented. The range of people who are let down by the current law is considerable. They include adults with severe learning disabilities, people with autism, people with mental health problems, victims of accident, people who develop brain damage and those who lose mental capacity later in life, including those with dementia.

1.4 The current law is also unclear about the legal rights and obligations of an individual who cares for a person who lacks the capacity to make decisions for themselves. Carers are uncertain about what decisions they can and cannot make.¹ New legislation would give clarity to carers on what they can legally do for the people they look after. Legislation would give carers the legal basis to make informal day-to-day decisions on behalf of someone who lacks capacity provided they exercise their authority in the best interests of that person. Professionals will also be clearer about how to represent the interests of people who lack capacity with whom they are working.

1.5 The current law gives a number of different answers to defining mental capacity. There is no statutory definition of mental capacity. It may not be clear whether an individual lacks capacity in relation to a particular decision. New legislation would ensure that the variety of different tests would be replaced with a single, straightforward statutory definition. This would introduce certainty and clarity. A definition of capacity would relate to a particular decision and would rest on an ability to understand the information relevant to that decision. Legislation should also give people greater rights to have a say in their own lives and to make their own decisions, unless they have been independently assessed as unable to do so.

1.6 The MDA believes that procedures are needed to resolve disputes and difficulties. There is currently no legal mechanism for resolving problems about personal care and welfare. A person who has diminished or fluctuating capacity may not be able to choose a person to make decisions on their behalf. These issues would be addressed in new legislation—for instance, the new Court of Protection would have the power to make decisions about the care or welfare of a person who lacks the capacity. The judicial option would be available where disputes arose and would provide an easy means of appeal if disagreements cannot be resolved.

¹ In this submission and the appendices, "carers" is used to refer to friends and relatives who provide unpaid care. Those who are engaged in the provision of care services are referred to variously as "professionals", "care workers" or "paid carers".

1.7 *The MDA Principles for Reform*

- People should be treated as individuals and their right to make their own decisions should always be respected. The law should assume that people are capable of making decisions unless the contrary is proved.
- Capacity should be determined in relation to a particular decision at the material time and should avoid generalisations that may unnecessarily restrict a person's right to make their own decisions.
- People who have difficulty making decisions should be supported to make their own decisions rather than having decision-making taken out of their hands.
- Where someone needs support to make a decision or a decision is being made on their behalf, they should have the right to the support of an advocate to help them make the decision and to ensure that they have a say in the decision-making process.

1.8 Although the first three principles are enshrined in the preliminary clauses (2–4), the MDA does not feel that the Bill currently contains sufficient mechanisms to ensure that these principles are implemented in practice. This is why we are continuing to press for the inclusion of advocacy and advance statements on the face of the Bill and for additional safeguards in relation to the General Authority (see Sections 5b: pp 20–24; 5a: pp 18–19; and 4.5: pp 8–12 respectively, for full responses).

2. SUMMARY OF MDA KEY RECOMMENDATIONS FOR ADDITIONS AND AMENDMENTS TO THE BILL

2.1 *General*

- Name of the Bill should be amended to the Mental Capacity Bill to reflect the presumption of capacity enshrined in the Bill.
- Presumption of capacity should be moved from clause 3 to clause 1 to reflect and promote its fundamental importance.

2.2 *General Authority*

- General Authority should be explicitly subject to the presumption of capacity.
- Clause 6, subsection (1)—“or person reasonably believes that P lacks” to be deleted.
- Consent in medical treatment to be removed from the remit of the General Authority.
- Significant decisions removed from the remit of the General Authority, unless justified by immediate necessity.
- The General Authority should not be assumed but should instead be triggered, for instance a case conference involving all those concerned with a person's care.
- The continuing need to act under the General Authority should be reviewed as part of a person's care programme.

2.3 *Restraint*

- Throughout the Bill, restraint should always be justified only if risk of serious harm is immediate (for example clause 7 (General Authority), clause 10 (LPAs)).

2.4 *Monitoring*

- The Bill should create a duty on local authorities to intervene in cases of suspected abuse, including abuse of the General Authority.

2.5 *Lasting Powers of Attorney (LPAs)*

- Clarity on the parameters for LPAs is needed, comparable to that given on the powers of Deputies in clauses 17 and 18.
- LPAs must be established within a clear hierarchy of decisions, in which they should “trump” other powers with the exception of Advance Directives and decisions of the Court of Protection.

2.6 *Deputies*

- Deputies should be made subject to Advance Decisions.

2.7 *Court of Protection*

- Court of Protection should be required to investigate potential conflicts of interest on appointment of Deputies and on the activation of LPAs.
- The Court of Protection should be made accessible to adults with impaired capacity.
- Legal aid and other financial assistance should be given to all such adults to support applications to the Court.

2.8 *Advocacy*

- There should be a legal right to access independent advocacy when formal powers are applied for, and a subsequent duty on the Secretary of State to provide sufficient advocacy services to deliver this.
- Advocacy support should be available if required when significant or life-changing decisions are contemplated under any of the powers established in the Bill.
- Individuals without other formal or informal networks of support should be prioritised for advocacy support.

2.9 *Other significant omissions*

- Appointeeship system to be regulated under the Mental Incapacity Bill, with appointees subject to the same list of duties as other substitute decision-makers.
- Advance statements to have superior status to other expressions of “wishes and feelings”.
- Assessment should be defined within the Bill.

3. MDA RESPONSE TO SPECIFIC COMMITTEE QUESTIONS

3.1 *Was the consultation process preceding the publication of the draft Bill adequate and effective?*

Yes. As noted above, the proposals set out in the Bill have been the subject of extensive consultation for 14 years. However, the MDA has a particular concern relating to the General Authority (clauses 6 and 7), which during the consultation process was presented as a mechanism for carers to take day-to-day decisions on behalf of a person who lacks capacity. The General Authority as presented in the Bill is far broader and the MDA has several suggestions as to additional safeguards to protect the rights of people with impaired capacity from abuse under the General Authority. See pages 8–12 of this response for the MDA commentary on the General Authority.

3.2 *Are the objectives of the draft Bill clear and appropriate?*

In parts. The draft Bill is clearly intended to put in place a legal framework to allow decisions to be taken for people who lack capacity. Only in clause 2, subsection (3) does the Bill refer to the need for supported decision-making. The MDA is concerned that the emphasis of the draft Bill is about making decisions on behalf of people who lack capacity rather than maximising decision-making abilities as set out in clause 3 of the Bill. This misplaced emphasis is reflected in the current title, which the MDA wishes to see changed to the Mental Capacity Bill to reflect and reinforce the presumption of capacity.

3.3 *Does the draft Bill meet these objectives adequately?*

In parts. In general terms, the mechanisms set out by the Bill meet the objective of allowing people to plan for future incapacity—the major exception to this being the omission of advance statements. The objective of giving carers the right to have a say in decisions made about a person they care for is also met effectively (clause 4). The General Authority and the various formal mechanisms will allow carers and care workers to operate within a comprehensive legal framework. However, our major concern lies with people born with impaired capacity and those who lose capacity without making provisions for this. We feel that this group will not in practice be fully empowered by the Bill to be involved in decisions taken about them or to maximise their ability to make their own decisions.

3.4 *Might lessons be learned from similar legislation already implemented in Scotland or elsewhere?*

Yes. Section 1, clause 2 from the Adults with Incapacity (Scotland) Act 2000 would strengthen the protection for adults with impaired capacity in the initial clauses of the English Bill:

“There shall be no intervention in the affairs of an adult unless the person responsible for authorising or affecting the intervention is satisfied that the intervention will benefit the adult and that such benefit cannot reasonably be achieved without the intervention”. Please see Annex 6.3: pp 36–39, for a detailed MDA commentary on similar legislation in other countries.

3.5 *Are there relevant issues not covered by the draft Bill which it should have addressed?*

The MDA believes that the following issues should have been addressed by the Bill:

- Advance Statements—see Section 5a: pp 18–19.
- Advocacy—see Section 5b: pp 20–24.
- Appointeeship—see Section 5c: pp 25–26.
- Assessment—see Section 5d: pp 27–29.
- Public Law Protection for Those at Risk—see Section 5e: p30.

3.6 *In what other ways might the draft Bill be improved?*

The MDA key recommendations for additions and amendments to the Bill are given are summarised in Section 2: pp 3–4. All recommendations are in bold in the text that follows.

4. MDA COMMENTARY DRAFT MENTAL INCAPACITY BILL

Clauses 1–5—Key Principles

4.1 *Approach to Capacity*

The MDA supports the Government’s proposals to create a more coherent approach to mental capacity and is supportive of the new test of capacity, the presumption against lack of capacity and the need for the minimal intervention in people’s lives.

4.1.1 A functional approach to capacity will mean that incapacity will be considered in relation to a particular decision or set of decisions, rather than based on a diagnosis of an individual’s condition. It is also necessary to take account of the particular needs and values of people from different minority ethnic communities or faith groups.

4.1.2 The Bill should state that religious and cultural factors should be taken into account when making decisions on capacity to consent. Capacity is seldom entirely present or entirely absent. The MDA believes that the intention behind legislation should be to maximise each individual’s capacity for decision-making. The emphasis should be on how decisions are made, how the consequences are communicated and how the facts can be broken down to aid decision-making.

4.1.3 Given that the emphasis in the Bill should be on maximising decision-making, the MDA recommends that the presumption against lack of capacity should be set out in clause 1 of the Bill. The Bill should also be named the Mental Capacity rather than the Mental Incapacity Bill.

4.2 *Definition of Capacity*

The definition of capacity in the draft Mental Incapacity Bill drops the diagnostic threshold that was set out in the Law Commission’s definition of capacity, namely a “disability or disorder of the mind or brain . . . which results in the disturbance of mental functioning”. The MDA supports this approach. This is because we had reservations about the potential for this new legislation to adopt the definitions set out in the Mental Health Act, particular because “mental disorder” might wrongly be equated with the criteria for compulsion. In addition, it would risk stigmatising or prejudicing people who need support with decision-making. Organisations representing people with a learning disability and older people felt that the term mental disorder would be misleading and not adequately describe their client group. Removing the diagnostic criteria will also mean that all the conditions that result in incapacity would be included within the new definition and ensure that a person will not need to have a prior diagnosis in order to have impaired capacity.

4.3 *Inability to make decisions*

We are concerned that by not expressly stating that clause 2 relates to the “material time” the decision is to be made, the functional approach to capacity is watered down. We therefore think that clause 2 should include the term “at the material time”. This would reinforce the functional approach to defining capacity and that the approach is decision-specific. It will also emphasise that giving and obtaining consent is a process and not a one-off event.

4.3.1 Clause 2, subsection (1)(d) envisages that there will be cases in which a person cannot communicate any decision. The clause implies that all forms of communication should first be considered, including sign language or any other means. We agree with this approach but we think the Bill must make supporting communication an explicit requirement. This is because an apparent lack of capacity may be, in fact, the result of communication difficulties rather than incapacity. Therefore, the MDA wants legislation to place an express duty on assessors to support a person to communicate their decision before a finding of incapacity is made. Mental capacity legislation should create an obligation on assessors to provide more information in order to empower people to make decisions that they are capable of making. Indeed, provision of information is central to the consent process. People should not be disadvantaged by lack of information or support to make their own decisions or indeed a shortage in resources that prevents this information from otherwise being made available. The parameters around the meaning of “all practical steps” to support decision-making (clause 2, subsection 3) will need to be clearly established.

4.3.2 Health and social care professionals often need help from those in day-to-day contact with the person who can identify and sometimes meet their communication needs. In some cases, specialist staff such as speech therapists may need to be brought in to assist with verbal and non-verbal forms of communication. If at all possible, the person should be assisted to make and communicate their own decision by providing information in non-verbal ways if appropriate. In addition to clause 2, subsection (1)(d), the MDA believes that clause 2, subsection (3) should state that “a person should not be treated as unable to make a decision or unable to communicate his decision unless all practical steps to help him to do so and to assist and support communication have been taken without success”. Moreover, it should build on the Law Commission’s wording which states that “a person should not be regarded as unable to understand information if he is able to understand a simple explanation of that information in broad terms and in simple language”.

4.3.3 The proposed Code of Practice on assessing capacity should promote a person-centred approach to decision-making, which considers how a person communicates, how a decision is made and how can the consequences best be communicated to that individual. It should also consider how a person could be involved where some of the decision-making needs to be done by others. This Code of Practice should also provide guidance on methods of assessment and how different forms of communication, including use of simple language, pictures, audiotape and communication aids, local advocacy support and advance statements, can help decision-making. In other cases, new technology can be used to make the decision and its consequences more visible. The Police Service Guide to Vulnerable Witnesses provides a good example of a person-centred approach to communication with people with learning disabilities.

4.3.4 The MDA supports the recommendation that a decision should not be regarded as invalid because it appears to be an unwise or irrational decision. We remain concerned that it might provoke a more detailed examination of whether an individual has the capacity to make a decision. Many people make unwise decisions but that should not make those decisions invalid.

4.4 *Best interests*

The MDA supports the best interests criteria set out in clause 4. The most important factor is the ascertainable past and present wishes and feelings of the person concerned; and the need to permit and encourage the individual to participate as fully as possible in anything done, or any decision, affecting him or her. We support the decision to extend the factors proposed by the Law Commission, to include consideration of whether there is a reasonable expectation of the person recovering capacity to make the decision in the foreseeable future. The MDA understands that it may not be practicable to consult with all family carers, particularly in cases of distant relatives who have not been involved in decision-making, as this may not be regarded as reasonable (clause 4, subsection (d)). However, there should be an expectation on professionals to make proper enquiries to identify all interested parties. Moreover, we are concerned that the views of others may not need to be sought if it is not “appropriate” to consult them (clause 4, subsection (d)). This may lead to subjective judgements about the appropriateness of a carer to represent a person’s views or to challenge the decision of professionals.

4.4.1 We are very concerned about the wording in clause 4, subsection (3)(b) which states that the duty extends to circumstances in which it is “reasonably believed” that someone lacks capacity. This would allow some people, presumably acting under a General Authority to act, to impose their own views of what is likely to be in the incapacitated person’s best interests, rather than effectively applying the best interest criteria, or to impose their views without first taking all practical steps to enable a person to make their own decision.

4.4.2 In relation to decisions made on behalf of a person without capacity, we support the Law Society's recommendation that decisions must be made in their "best personal interests". This emphasis would stress that priority should be given to identifying those issues most relevant to the individual, rather than to the decision-maker or other people. Without such emphasis there is a risk that the individual's own best interests will not in fact be the paramount consideration.

4.5 *Clauses 6–7—The General Authority*

The General Authority will give protection to much informal substitute decision-making that currently takes place outside any formal legal framework. This will give a legal context for all day-to-day decisions that are made, such as paying bills and giving medication. In this sense, it codifies the existing legal situation as established in case law.

4.5.1 The MDA acknowledges the need in certain situations to empower carers to take effective decisions on behalf of people with impaired capacity. The General Authority serves this purpose well, and the restrictions set out in clause 7 should prevent the worst abuses of its powers. However, the MDA is concerned that in circumstances where the interests of carers and those they care for are not aligned, the General Authority still offers too little protection for the rights of people who may have difficulty making or communicating decisions.

4.5.2 In these circumstances, the General Authority may tend to undermine the presumption of capacity. With no counterbalance or system of protection for people who may lose the ability to make their own decisions under the General Authority, this may in practice lead to a presumption of incapacity. To prevent this, the MDA believes that the General Authority should not be assumed but should instead be triggered, for instance at a case conference involving all those concerned with a person's care. At this point, all the principles of the Bill set out in clauses 2–4, not least the presumption of capacity and the need to take all practicable steps to support decision-making, should be applied. The decision that the General Authority may be applied to the individual in question should be recorded; and all those using the General Authority should be able to justify its use, if challenged or investigated.

4.5.3 The continuing need to act under the General Authority should also be reviewed as part of a person's care programme. By this means, decision-making mechanisms would be integrated into a person's overall care plan (through the care programme approach, person-centred planning or single assessment process as relevant), reducing the need for additional bureaucratic processes. However, it is important to note that adults with impaired capacity who are not in contact with services will not be able to benefit from this safeguard.

4.5.4 As it stands, the General Authority will enable people to make decisions for others if the person reasonably believes that the other person, P, lacks capacity. We agree that the General Authority should be subject to best interests (clause 6, subsection (6)) but this assumes that a person lacks capacity and that a decision needs to be taken in their best interests. The MDA argues that the General Authority to act should also expressly state that it is subject to clause 3, the presumption against lack of capacity as well as the best interest criteria in clause 4.

4.5.5 The Bill should also strengthen the expectation on carers and care workers to take all practical steps to support people to make decisions that they are capable of making, before taking decisions on their behalf. The starting point for carers and care workers should be on maximising decision-making and supported decision-making rather than making a substitute decision under a General Authority. In line with our comments in relation to the "best interest" criteria, the current wording, "reasonable belief", runs the risk of allowing the person acting under a General Authority to circumvent the requirement to assess capacity before making decisions on another person's behalf. The MDA therefore recommends that "or person reasonably believes that P lacks" in clause 6, subsection (1) is removed from the Bill.

4.5.6 The MDA's concerns in relation to clause 6 highlights the need for people who have difficulties making or communicating decisions to be able to access support from independent advocates. Without the involvement of an advocate, and with no requirement for capacity to be independently assessed, the General Authority gives statutory recognition to a "closed relationship" that will not be monitored by any third party, and may therefore be open to abuse. The General Authority was initially presented to stakeholders as a mechanism by which "day to day" decisions could be taken by carers, without the need to resort to formal processes, so minimising bureaucracy. Yet in the draft Bill, no limitation is placed on the types of decision that can be taken under the General Authority, other than that in all the circumstances it is reasonable. The MDA is concerned that the Bill makes no distinction between a day-to-day decision taken by a parent or carer and bigger one-off decisions such as medical decisions or where a person lives, taken in the best interests of another individual who lacks capacity.

4.5.7 We therefore recommend that the Bill removes some decisions from the scope of the General Authority. The MDA believes that the Bill should make it explicit that the General Authority does not authorise a carer or professional to make all decisions on medical treatment, in particular to consent to treatment. The carers' ability to make all decisions on medical treatment should be restricted to the administration of prescribed medication and decisions about whether to provide non-prescriptive medication such as pain killers.

4.5.8 Other medical treatment decisions should be made by the appropriate health professional under the General Authority but subject to additional safeguards. The safeguards would include an obligation for the health professional to carry out an assessment which confirms that the person concerned is without capacity to consent, that it is in the best interests of the person concerned for the treatment to be carried out and that the person has the support of an advocate to assist the person to participate in the decision as fully as possible.

4.5.9 Where it is found that a patient lacks the capacity to make a decision, the health professional, in consultation with the full clinical team and the patient's family, friends and carers, must make a decision in the patient's best interests. Every effort should be made to reach a consensus between relatives, carers and health professionals. This would include a case conference bringing together all interested parties, which would ensure that all those who know the person would have the chance to speak for their interests. Where there is a dispute as to whether these interests can be properly defined, the case should be referred to another health professional that is not part of the treating team for a second opinion. In cases where a health professional's view is substantively challenged and agreement cannot be reached it may, as a matter of last resort, be necessary to refer the case to the Court of Protection. These safeguards should be made clear on the face of the Bill. This would strengthen carers' and carer workers' rights through the requirement on health professionals to consult with them before making a decision on a person's best interests.

4.5.10 The MDA also proposes that other decisions that could potentially have a significant impact on the individual or amount to a significant change in circumstances should not generally be made under a General Authority. This would cover decisions such as a change in where someone will live, including following hospital discharge, and major financial decisions. Where a person is in contact with services, these decisions should already be taken as part of their care planning process. The new legislation would simply require carers and care workers to obtain a single order from the Court of Protection to legitimately make these decisions.

4.5.11 A significant change in circumstances would need to be assessed on a case-by-case basis, but would include a change of carers, such as a move away from a residential home to supported living. We, therefore, consider that decisions about where someone lives should be subject to similar safeguards as medical treatment, including ensuring that where possible there is a case conference about the proposed change. The MDA would argue that a decision taken under the General Authority in those circumstances would not be reasonable under clause 6, subsection (1)(b). It should instead be subject to the approval of the Court of Protection if an attorney or Deputy had not been appointed. The exception to this would be if a decision had to be made urgently or in an emergency, provided the decision was made for the benefit of the person and in their personal best interests. Similarly, other important decisions, for instance around childcare, should also not generally be taken under the General Authority.

4.5.12 The universal scope of the General Authority also requires a substantial public information campaign to inform all current and future carers of their rights and responsibilities under this legislation. The MDA is concerned that the subtle checks and balances set out in part 1 of the Bill will be lost on many carers if they are not given full guidance and support. The MDA is pleased that a separate Code of Practice will be developed to offer carers guidance in this area. It is important that carers are briefed on their responsibilities and that these responsibilities should only be retained if appropriately discharged.

4.5.13 Practical examples to illustrate the concept of reasonableness might be a useful method of conveying this both to carers and people who may have difficulties making decisions for themselves. The MDA proposes a duty on the Lord Chancellor or his successor to provide all information to stakeholders on the Bill that he feels necessary, in addition to the requirement to publish Codes of Practice (clause 30). Supplementary to this, clause 30, subsection (7)(b) should be amended to that the Codes of Practice must be taken into account where relevant in court cases, particularly in the Court of Protection. As stated above, carers should be able to demonstrate to the Court or any other investigating agency that their application of the General Authority has conformed to the principles set out in the legislation. This may involve the need to keep notes of why a particular decision was taken, or what steps were taken to enhance the ability to make decisions of a person with impaired capacity.

4.5.14 The MDA supports the concept of the General Authority to act reasonably—the reasonableness relating to the person in that situation. In cases in which the act involves expenditure, it should be lawful to apply that person's money where the purchase can reasonably be held to be for the benefit of that person. This should be an additional requirement on the face of the Bill. For example, using monies in order to take someone on holiday may be of benefit for the individual but using that money to buy a car for the carer may not be viewed as delivering a direct benefit for the individual.

4.5.15 Restrictions on the General Authority

The MDA supports the proposals in clause 7 that ensure that a person will not be forced to comply with a proposed action to which he or she resists unless it is essential to prevent a substantial risk of significant harm to the person concerned. However, we believe that this power should be based on an assessment of immediate harm to justify its use. It will clarify how carers will be accountable and provide protection from abuse where the confinement is justified. We prefer the term used in the Bill “resists” to the Law Commission's wording “objects”. An individual may not actively object to confinement, particularly if the

person has communication difficulties, but may still resist the proposed course action. The Bill should also place a requirement on local authorities to intervene in the General Authority where they do not think that it is being used in the best interest of the individual and to provide a check in cases where a person is detained in order to avert a substantial risk of significant harm to himself, wherever that person lives.

4.5.16 We agree that a General Authority should not be able to overrule a power of attorney or a decision made by a Deputy appointed by the court. However the borderline between the General Authority and the Deputy system is difficult to draw. eg do the informal arrangements cover all medical matters until the decision is challenged? At what point should a matter rest with the court rather than a General Authority to act?

4.5.17 The MDA is generally inclined towards reserving to the courts decisions on withdraw of medical treatment, such as in cases involving PVS, and other forms of medical treatment such as sterilisation. This should be made clear on the face of the Bill.

Clauses 8–13—Lasting Powers of Attorney (LPAs)

4.6 LPAs—Overall recommendations

One of the major attractions of a Lasting Power of Attorney (LPA) is that it involves the Donor, whilst he or she has capacity, in nominating the person they would wish to make decisions about personal welfare and property and financial affairs. As with all the decision-making powers included in this draft Bill, the MDA seeks clarification of the parameters of the LPA remit. We would want these at least covering the same remit as that proposed for the Court of Protection and set out in clauses 17 and 18. In addition, the Court of Protection/Public Guardian should be required to investigate potential conflicts of interest when LPAs are registered.

4.6.1 The current approach to informing third parties that an application for an Enduring Power of Attorney (EPA) has been made can be administratively complex and not necessarily wholly reliable. We have some sympathy with the proposal to reduce the numbers of people who are notified, including the limiting of notifications to only the Donor and Donee(s). An important issue here, however, lies in ensuring that the Donor is not subject to any undue influence when creating the LPA. Unless a third party—ie someone other than the Donor and Donee(s)—is required to be notified by the Public Guardian that an application has been received, the opportunity would exist for Donee(s) to insist to the Donor that no-one else is informed of the application. The MDA feels that provision should be made for at least one other party to be notified of the application, beyond the Donor, Donee(s) and the person certifying the Donor's mental capacity. We suggest that the name(s) of this nominated party is not disclosed to the Donee(s), to further avoid issues of undue influence. Where the application is made by the Donee, we suggest that regulations set out who can and cannot be included as the third party (for example, excluding the Donee(s) partner, children or other immediate family).

4.6.2 Information and training will be needed for Donees to understand the powers that they hold, and the responsibilities placed on them. In particular, this will be needed in respect of understanding that their powers under LPA arrangements are only effective at such times as they are active. At other times, the Donor will be in control of decisions in those areas of life otherwise covered by the relevant LPA(s). The MDA welcomes this principle. Those holding LPAs should at all times be subject to the Best Interests principle, even when the Donor has capacity.

4.6.3 We agree with the proposals that a Donor can choose to give to the Donee the power to refuse consent to life-sustaining treatment, and to give or refuse consent to treatment to which an existing advance decision relates. However, we suggest that if an LPA specifies that it is to cover all health and personal welfare decisions, it should be assumed this includes these decisions and the provisions relating to advance decisions; and that the relevant application form should make this clear.

4.6.4 The MDA supports the proposals in clause 10 that the Donee(s) of an LPA will not have the power to force the Donor to comply with a proposed action to which he or she resists. However, we are concerned with the wording of the proviso, “unless it is essential to prevent a substantial risk of significant harm to the person concerned”. As with our concerns about the General Authority, the MDA believes this should be changed to “unless it is essential to prevent an immediate risk of significant harm to the person concerned”.

4.6.5 It will be critical for Donors to understand that, at times when they have regained capacity, they have the power to revoke a registered LPA. It will also be essential that they are supported to be able to act on this power. This is a specific area where access to advocacy will clearly be of major benefit to individuals.

4.6.6 The proposed LPA arrangements suggest a welcome flexibility in how decisions are made during times of fluctuating or reducing capacity. The MDA seeks, however, clarification on whether the intention is that those holding a personal welfare LPA cannot take decisions on health matters at times when “P” has capacity, and whether this would also apply to other, “personal welfare”, aspects held within the LPA.

4.6.7 We would also propose the following hierarchy of decision-making:

- If a decision is within the scope of how an individual LPA (or Court-appointed Deputy) has been set up, the LPA (or Deputy) would “outrank” the General Authority.

- If a decision is within the scope of how an individual LPA has been set up, the LPA would “outrank” a Deputy.
- The Court may direct an LPA on decisions on which the LPA has the power to act if P lacks capacity to make those decisions; and can give the consent/authorisation to act which the LPA Donee would have to obtain from P if he had capacity to give it.

4.6.8 Fundamental to this “hierarchy” is the understanding that it is based on the principles within the draft Bill. In particular, that these powers to act on behalf of “P” only exist whilst the person lacks capacity. MDA believes this critical issue will require training, advice and information for all parties.

4.6.9 Capacity in the context of LPAs

The Donor must have capacity when creating the LPA. This is to be assessed by “a person of a prescribed description” (but this person cannot be a Donee), and a certificate to that effect must accompany the application. In making the application to register the LPA, the Donor must sign to say the prescribed information has been read to him (or he has read it), and that he intends the authority conferred under the LPA to make decisions on his behalf in circumstances where he no longer has capacity.

4.6.10 The MDA is concerned that “certification” seems to go against the principle, set out in clause 3 of the draft Bill, in which the starting point is always that capacity is assumed to exist. We make a specific recommendation on this matter in the separate section in this paper on Assessment. Our view at present is that, if any such requirement is to be established, this should apply equally to Donors and Donees—not least given that one of the “qualifying” factors for Donees is that they have mental capacity. (See also 5d.11, pp 28–29.)

4.6.11 Relationship to Enduring Powers of Attorney

These proposals significantly reform existing arrangements for Enduring Powers of Attorneys in respect of notifying named parties. Currently, a comparatively long list of whole blood and half blood relatives must be informed (where these exist) that an application has been made. It is those “third parties” who are most likely to lodge an objection over the creation of particular EPAs. As noted above (4.6.1), the MDA believes that a requirement to notify at least one party outside of the LPA arrangement should be retained.

4.6.12 One of the major concerns with current Enduring Power of Attorney (EPA) arrangements lies in the numbers, it is believed, of people acting under EPAs that have not been registered. Many of those holding an EPA for another person appear not to understand that registration is necessary. It will be important for Donees to be able to produce evidence that they hold those powers as near to the material time as possible and for all parties to understand that those powers are only held once registered.

4.6.13 LPA—personal welfare

Although an LPA must be registered whilst the Donor has capacity, it is only effective in terms of personal welfare decisions when the Donor lacks capacity. For people with fluctuating conditions this will be extremely important, as it will mean that decisions about health care should not be taken when the person has the capacity to make their own decisions. It will therefore be essential that guidance and training is in place, especially for Donees of LPAs, in order that they are able to make the distinction; and for health and social care professionals to understand that the creation of a personal welfare LPA does not mean that Donees will necessarily have the authority always to make those decisions. In particular, LPA Donees will need to have sufficient understanding to be able accurately to judge when the Donor has regained capacity in respect of those particular personal welfare questions. Nonetheless, the MDA welcomes the principle that personal welfare LPAs only take effect if at the material time the person lacks capacity, as this illustrates in practical terms that a lack of capacity is not always a permanent situation.

4.6.14 A personal welfare LPA can be set up to include the power to refuse consent to life-sustaining treatment, and to give this explicit authority to the Donee. We support this proposal. With respect to advance decisions, a personal welfare LPA can also be set up such that the Donee can give or refuse consent to the treatment to which an existing advance decision relates. We also agree with this proposal, but suggest that if an LPA specifies that it is to cover all health and personal welfare decisions, it should be assumed this includes these decisions and the provisions relating to advance decisions, and that the relevant application forms make this clear.

4.6.15 LPA—property and financial affairs

The registration of a property and financial affairs LPA would create a situation where the Donee can act as an “ordinary” power of attorney even when the Donor still has capacity; but, unlike existing arrangements, it will also continue after the person has lost capacity. This suggests that this proposed LPA would mirror both the existing ordinary Powers of Attorney (which tend to relate to a specified, one-off financial event) and those for Enduring Powers of Attorney, whereby once registered a Donee has ongoing

authority over the person's money irrespective of whether or not their capacity fluctuates. It will be important here for Donors to understand that, at times when they have regained capacity, they have the power to revoke an LPA and could choose to do so in respect of financial matters. It will also be essential that they are supported to be able to act on this power.

4.6.16 Banks and other financial institutions may find it easier to know that, once a financial affairs LPA has been registered, they will be dealing consistently with the Donee(s) rather than dealing with the Donor some of the time and the rest of the time with the Donee(s)—especially as it is unlikely they will have sufficient expertise to be able to ascertain whether or not a Donor has capacity at the material time. This has been the arrangement with regards to EPAs for many years, and does not appear to have caused significant problems. Nonetheless it is not consistent with the overall notion of incapacity as a situation that fluctuates for some people.

4.6.17 The MDA suggests that further consideration be given as to how Donors might regain control over their finances in practical terms during times of capacity other than by revoking the relevant LPA. Further advice may be needed to banks and other financial institutions if it is possible that they may deal with the Donor of an LPA that is registered for financial affairs at times when the Donor has capacity, and with the Donee(s) at other times. Support to Donors to supervise Donee(s) during times of capacity will also be essential. The MDA believes this would also form an important part of advocacy support.

4.7 *Clauses 14–22—Powers of the Court/Court-Appointed Deputies*

Court Appointed Deputies will replace the current receivership system. As with LPAs, Deputies will be able to take decisions, only if so appointed by the Court of Protection, across the full range of financial, health and welfare issues. Deputies can be appointed to make decisions on one or more strand of decision-making. Additionally, if a trust corporation is appointed Deputy, it can only be in respect of property and affairs. The court will be able to appoint more than one Deputy to act on behalf of an individual who lacks capacity.

4.7.1 The MDA welcomes the extension of powers for Deputies to include personal welfare and property and affairs. We acknowledge the need for this set-up should the person be born with impaired capacity, or lose their capacity without having made previous arrangements to nominate an LPA. However, there need to be full checks and balances to ensure that decisions made by Deputies on behalf of people who lack capacity are in their best interests. Whilst we welcome the restrictions on Deputies set out in clause 20, we feel that they does not go far enough in safeguarding the rights of people who lack the capacity.

4.7.2 We are concerned that the Court of Protection should only appoint a Deputy when an independent assessment of capacity to take a particular decision has been made. Also, the appointment of a Deputy is a key moment when we believe a right to access independent advocacy should be triggered. This also highlights the need for people who have difficulties making or communicating decisions to be able to access support from independent advocates. Without the involvement of an independent third party, assumptions may be inadvertently made about the capacity of that person.

4.7.3 *Restrictions on Deputies*

We welcome the restrictions laid out in clause 20, particularly those relating to settling property or the execution of a will. However, we feel that there needs to be further restrictions. The court should be given the power to investigate any conflict of interest, whether professional or personal, before an application for a Deputy is approved. This will ensure that the applicant for Deputy is a suitable candidate. Furthermore, the court needs to be given powers to make checks about the competency or capacity of the applicant to carry their functions as a Deputy—eg the Court may decide that a person who is already a Deputy for a number of people may be incapable of taking on additional Deputy responsibilities.

4.7.4 These checks should include liaising with the Criminal Records Bureau (CRB) and local authorities to ensure that the applicant is not on any statutory lists or registers that preclude people from working with vulnerable adults. Finally, and unlike the MDA's position on LPAs, we do not believe that Deputies should always be able to give consent to the withdrawal of treatment. Rather, we prefer a requirement for a single order of the Court of Protection where circumstances permit.

4.8 *Clauses 23–29, Clause 32—Advance Decisions*

The MDA strongly supports the inclusion of Advance Directives to refuse treatment in the draft Bill. This will clarify an existing area of common case law, and will enable an individual's expressed views, regarding withholding or withdrawing of treatment, to be adhered to even when the person concerned has lost capacity. We support the tests of validity and applicability that are detailed in clause 25 and feel they will provide considerable safeguards to prevent advance directives being abused. We particularly welcome the inclusion of clause 32, which will make it a criminal offence, punishable by imprisonment or a fine, to conceal or destroy another person's advance decision as it will validate and strengthen the power and influence of the advance decision.

4.8.1 The MDA welcomes the regulations that require both those acting under the powers of the General Authority and the “Welfare” Lasting Power of Attorney to be subject to clauses 23 to 25 (advance decisions to refuse treatment). The MDA, however, feels it is an omission for the Bill not to require court appointed Deputies to also be subject to clauses 23 to 25. This is particularly important because currently Deputies will be given the power to give or refuse consent to the carrying out or continuation of a treatment. This will provide a legal loophole that could be exploited in order to override a person’s advance decision.

4.9 *Clauses 34–46—The Court of Protection*

The MDA supports the principle of a unified Court of Protection with High Court status, and the provisions for it to have a regional presence. The MDA welcomes the provision for the Court to make single orders on important decisions. However, the MDA would be concerned if the costs of such orders were so high that it would act as a disincentive. In terms of other costs that might be incurred when making an application with the Court of Protection, the MDA seeks an assurance that people who lack the capacity can apply for legal aid to cover their legal costs. All Court of Protection judges and staff will also need to have detailed training to fully understand the impact of this new legislation. Resources will also need to be found to secure training for Court judges and employees on the needs of the various client groups they will be dealing with.

4.9.1 The Court of Protection must be fully accessible to both carers and adults with impaired capacity. The accessibility of the Court, particularly in relation to single orders, will be particularly important if the Committee accepts the MDA recommendation that certain decisions should be removed from the remit of the General Authority. Finally, the MDA would like to seek an assurance that the Court of Protection procedures will apply the Speaking up for Justice measures, which were set up by the Youth and Justice Criminal Act 1999, when necessary.

4.10 *Clauses 47–49—The Public Guardian/Lord Chancellor’s Visitors*

The MDA has a general concern that the implementation of any future Mental Incapacity Act will not be effectively monitored. Our recommendation is that the Public Guardian/Lord Chancellor’s Visitors randomly inspect a given percentage of carers holding formal substitute decision-making powers each year, and then report on the findings of these inspections to Parliament. Allied to our proposed duty on the Lord Chancellor to provide information as requested, this would increase the likelihood that the principles of the legislation would be respected in practice by carers and care workers.

5a. OMISSIONS FROM THE BILL—ADVANCE STATEMENTS

The MDA suggests that the Bill should enshrine in law a person’s right to make an advance statement. A person should be able to specify their wishes and plans in advance in case they become unable to make decisions for themselves.

5a.1 An advance statement is a declaration that an adult gives about the care and support they would wish to receive. One of the types of statement that can be given is an advance directive where an adult refuses in advance a specific medical treatment or procedure. At present, this is the only form of advance statement that is legally binding on professionals, as established through case law. Advance directives are also included on the face of the draft Bill.

5a.2 Advance statements and advance directives provide the opportunity for adults with capacity to state their wishes and plans in advance, in case in the future they become temporarily or permanently unable to make decisions or communicate their wishes. Advance statements also protect the principle of consent and ensure that crucial life decisions are not reliant upon the assumptions of professionals involved, particularly with regards to decisions about quality of life. This is why the MDA believes that advance statements should also appear on the face of this Bill.

5a.3 Advance statements enable an individual to express their views and preferences on a large range of issues, including:

- domestic arrangements;
- treatment preferences;
- financial arrangements;
- childcare arrangements;
- clarification of who to disclose information to, and the limits of what can be discussed; and
- whom they would nominate as a “nominated person” in future Mental Health legislation.

Furthermore, advance statements provide both additional safeguards and direction for a person acting for someone who has lost capacity.

5a.4 The MDA proposes a requirement for a person acting under a General Authority, a “Welfare” Lasting Power of Attorney or as a Deputy appointed by the court of Protection to act in accordance with an individual’s advance statement. In Clause 2, subsection (2) the existence of an advance statement would provide guidance around the “practicable steps” to assist those helping someone who is unable to make decisions. In Clause 4, the existence of an advance statement would give a clear indication of all those involved in making decisions on someone else’s behalf of the person’s “best interest”, especially as an indication of the person’s “past and present wishes” (Clause 4, subsection (2)(c)(I)).

5a.5 Advance statements should be subject to the same conditions as advance directives, namely that advance statements meet the criteria of validity and applicability, and are deemed to be reasonable and in the person’s best interests. In addition, clause 32, which relates to destroying or concealing an advance decision, could also be extended to include advance statements.

5a.6 The Explanatory Notes published alongside the draft Bill state that “Many forms of advance statement will be relevant as the ‘past wishes of P’ mentioned in the best interests checklist in clause 4”. However, failure to state the legal position of an advance statement on the face of the Bill will undermine its value as a mechanism to plan for impaired capacity.

5a.7 The value of an advance statement is that it is an expression of the individual’s views and may be the only means by which the person can communicate this in the future. This gives it, as a document, substantial importance and as such there should be clear guidance about how it fits within the wider powers within the Bill.

5a.8 It is possible to legislate for advance statements, indeed it is required, in order to give clear legal guidance on their legal validity, the necessity for and boundaries to which professionals are obliged to follow their requests and the circumstances in which they can be overridden. Furthermore, as the Bill stands, an advance statement will not have the same legal status or validity as an advance directive and thus will not receive the same protection from abuse, undue influence when completed, or destruction.

5a.9 Advance statements would give effect to a person’s wishes and act as a safeguard in relation to the other formal powers under the Bill. Consultation of any available record of an advance statement would therefore be one of the “practicable steps” that must be taken (clause 2(3)) before an assessment of the person’s capacity is undertaken. This would reassure people that their views and wishes will be considered irrespective of any future incapacity and could offer concrete protection from neglect. In specific circumstances, it would be a positive opportunity for an individual to record their wish for them to receive life-sustaining treatment.

5a.10 In complex situations, advance statements could act as a vital communication tool, clarifying and informing decisions making for professionals and carers. Around the time of completion of an advance statement they will facilitate further discussion and future planning. This will be beneficial in later decision-making, potentially assisting in avoiding conflict and disputes. It would also prevent the lack of information or representation that can result in decisions being made that are contrary to the person’s views or culture.

5a.11 Advance statements could indicate whom the individual would and would not consider reasonable to act under the General Authority, should they lose capacity at some point in the future. This would clarify a potential area of conflict and provides a more accessible, less bureaucratic alternative to the “Welfare” Lasting Power of Attorney. It would act as another process by which an individual’s views could be considered; this is particularly important for those who are isolated and do not have someone in their lives who know them well enough to make decisions on their behalf under the powers of the General Authority.

5a.12 It is vital that everyone is aware of the existence of either an advance statement or/and an advance directive. We would hope there would be guidance on the importance of “registering” them with all the professionals involved, including both the medical and social care team. We suggest that this is clarified in further guidance regarding this area.

5b. OMISSIONS FROM THE BILL—ADVOCACY

The Making Decisions Alliance believes access to independent advocacy could be a vital mechanism for ensuring the needs and rights of the individual remain at the forefront of this Bill and that its overarching principles are fulfilled. It also strongly believes that access to independent advocacy could help prevent drawn out and distressing disputes and help avoid costly recourse to the Court. Consequently it believes that Government should take responsibility for providing the resources necessary to ensure that access to independent advocacy is available to those who need it. Annex 6.2 details recent Government initiatives that mention advocacy.

5b.1 *When should independent advocacy support be made available?*

Ideally, an individual should have access to independent advocacy whenever they feel they want or need it. However, we appreciate that in a world of limited resources this may not be possible. For the purposes of this Bill, we are particularly concerned that independent advocacy is available in the following situations:

- When capacity is being assessed in relation to a major life changing decision.

- When a major life changing decision is being made.
- When disputes around the above situations arise.
- When a court-appointed Deputy is to be appointed, a Lasting Power of Attorney is being set up or activated, or a single order of the Court is being made.

5b.2 In addition, the MDA believes that individuals without other formal or informal networks of support should be prioritised for advocacy support. This should be clarified in a Code of Practice on Advocacy in relation to Mental Incapacity.

5b.3 *What is advocacy?*

There are numerous definitions of advocacy in existence. The Independent Advocacy Consortium defines it as “taking action to help people to: say what they want; secure their rights; represent their interests; and obtain services they need”.

5b.4 Essentially, advocacy is about empowering people, by enabling them to be more actively involved in the decisions that affect their lives. A good advocate will possess the skills and training not only to help a person speak up for themselves, but also to establish what their preferences are, even when these cannot be communicated in conventional ways. They will also respect the particular needs and values of people from different minority ethnic communities or faith groups. An advocate is not there to express or impose their own views but to act as a facilitator and to support the individual to express themselves. In addition, they should be independent of the organisation that a person is dealing with to avoid potential conflicts of interest.

5b.5 There is a wide range of advocacy models available, including Citizen Advocacy, Peer Advocacy, and paid professional advocacy (see definitions in Annex 6.2: p32, 6.2.3). In some instances a person may need an advocate in relation to a particular decision, while at other times or for other individuals a longer-term relationship is more appropriate. The MDA does not believe that there is only one acceptable model of advocacy. The choice of advocacy used should be based on the individual’s own needs and wishes, and take account of what provision is available locally. However, regardless of the chosen model, the independent advocate must be adequately trained for their role.

5b.6 Advocacy is not the only way of ensuring that individuals who may have difficulty making decisions or expressing their views can participate in decision-making. Other support mechanisms such as mediation or interpretation services, service user self-help groups and legal representation at the Court of Protection may also play a valuable role. However, independent advocacy is an extremely valuable tool in securing an individual’s right and preferences.

5b.7 *The potential benefits of Advocacy in the context of mental incapacity legislation*

Ideally an advocate:

- is independent—has no axe to grind, no history, no vested or conflict of interests;
- can be a very effective safeguard, flagging up concerns or queries to the appropriate authorities;
- understands the abilities of the individual;
- is focussed on the needs and views of the individual and ensuring that these are given voice, not the people or institutions around them (person centred);
- is trained not to take a view of their own, only seeking to uncover or communicate the individual’s, BUT; and
- may be able to contribute to the assessment of capacity by highlighting what they know or can glean about the individual’s abilities or preferences.

5b.8 An individual may need an independent advocate because of a condition or disability they have, their life experience, their impaired ability to communicate conventionally or some combination of these. Their need may also stem from the type and importance of decision being made: individuals may need assistance to make some types of decision but not others. Even people who are incapable of making a particular decision may be enabled by an independent advocate to express or communicate preferences, which could assist those around them and make them feel sure that they are acting in the best interests of that individual. Such input could also help to develop an individual’s capacity to participate in making decisions over time.

5b.9 Alternatively, an individual’s life experience (often linked to their experience of how society and institutions have reacted to them and their impairment) may also have an impact on their ability to make certain decisions. An example would include someone who has lived in residential care for all or most of their lives or have lived with family members who have made all the key decisions relating to them. This person may be about to move into independent living and, although their condition may not be directly affecting their mental capacity, they might still need some initial or ongoing support around choices and decisions that affect their lives.

5b.10 Some people may have the ability to make such decisions but may not communicate in conventional ways. There is a risk that people may make inaccurate assumptions about the ability of these individuals to make decisions. Conversely, other people may appear to have highly developed communication skills that may mask difficulties in making certain types of decisions.

5b.11 *When in the Bill should access to advocacy be available?*

The draft Bill sets out a number of ways in which an individual will be able to make decisions on behalf of adults who lack capacity. The MDA feels that access to an independent advocate could be extremely beneficial to the person at the centre of these situations. They could ensure that every effort is made to utilise and accurately assess the capacity the individual has and that the person's viewpoint and preferences is explored and taken account of as far as possible.

5b.12 *Advocacy as a safeguard for the General Authority*

The draft Bill says very little about the mechanisms by which capacity will be assessed. However, in view of the wide powers under the General Authority, it is likely that in most cases an assessment of capacity will be made by the professional or carer most relevant to the particular decision to be made, rather than a person who is specifically trained to assess mental capacity.

5b.13 The MDA is concerned that those making assessments of capacity may not understand the wide range of conditions that can affect people's ability to make decisions or communicate their views or have all the skills, knowledge, time or up-to-date awareness of equipment, which may be necessary to accommodate these different impairments. It may also be particularly challenging to assess the capacity of people whose condition fluctuates.

5b.14 This is likely to be particularly important where life changing decision are being contemplated (see below). The MDA has consequently recommended that certain major decisions be removed from the General Authority and that other arrangements are put in place when such decisions are made (see Section 4.5: pp 8–12).

5b.15 The MDA believes the potential involvement of an independent advocate in such circumstances could help ensure the individual's capabilities are being respected and their views included. It could also help others ensure they are optimising the involvement of the individual in the decision-making process, accessing all the relevant information about the person and so helping them fulfil their legal duties. Similarly, when there is a dispute or a desire to appeal against assessment of capacity decision itself, the individual concerned may find the services of an independent advocate an essential safeguard in preventing loss of control over their lives and decisions.

5b.16 *Making major decisions or in important situations*

The MDA is concerned about how the General Authority is defined and where the line should be drawn between informal decisions and more important decisions. For example a decision on how an individual spends their days may not appear to be a major decision, but it could have a major impact on someone's quality of life.

5b.17 The MDA believes it is possible to set out some major life changing decisions or situations where access to an independent advocate will be vital to ensuring that the individual's needs are properly addressed and their preferences taken on board. If the person has been assessed as capable of making the decision, they may need such help to think through their decision or express their views; if not, an advocate can help the individual express their preferences.

5b.18 Among the major life changing decisions or situations the MDA believes access to independent advocacy support should be available are:

- invasive surgery;
- long term treatment with significant potential side effects and other major medical treatment;
- issues where the individual lives (including independent living options and hospital discharge);
- who they live with;
- what work they do or how;
- where they spend their day or time;
- who provides their personal care; and
- who manages their money.

5b.19 Disputed decisions

MDA members and advocacy organisations are often asked for assistance when conflict arises between the individual, their families and professionals involved. Clearly, each of these groups has legitimate needs, pressures and concerns of their own which should be acknowledged. However, the most important person involved is the individual and their views should usually take precedence. Mediation or Court action might be necessary to resolve this situation, but the involvement of an independent advocate in this process can ensure that the particular views and preferences of the individual are communicated effectively. (An opportunity for the individual to challenge the decision reached may also be necessary).

5b.20 Access to independent advocacy may be particularly important in dispute situations when the individual is feeling unable to represent their own views clearly, perhaps due to illness; if their views contrast or conflict with the needs and views of those around them; or if they are unconventional or quirky, as this could be interpreted by others as indicators of a lack of capacity.

5b.21 Advocacy Preventing Abuse

The General Authority envisages a very “closed relationship” between individual and carer which is not monitored by a third party to prevent or deal with disputes or potential abuse. The involvement of advocacy could reduce the risk of abuse. It could also support those with limited or fluctuating capacity to navigate existing complaints mechanisms such as PALS, ICAS or various Ombudsmen where the problems relate to statutory services.

5b.22 Advocacy as a safeguard when a Lasting Power of Attorney, a Deputy or a Single Order occurs

The MDA believes that access to an independent advocate could be a very valuable safeguard in relation to an appointment of a Lasting Power of Attorney, a Court appointed Deputy or when single orders of the court are being considered.

5b.23 An independent advocate could help explain and support a person through potentially confusing and alienating processes such as court hearings. An advocate could assist in exploring and explaining what the individual feels is in their best interests and support them in continuing to make those decisions they are able to make for themselves.

5b.24 Independent advocates could provide support when an individual is setting up an LPA or revoking it. They could help people with fluctuating capacity to insist that they do have capacity to take decisions and that an attorney or Deputy is not needed to act on their behalf. They could also assist an individual in supervising an Attorney around financial matters.

5b.25 Access to the advocate could be triggered by anyone involved in the case who felt the needs and views of the individual were being ignored or overridden.

5b.26 Proposals to ensure that independent advocacy is available to all adults with impaired capacity.

The Government should provide funding to ensure that every local authority area has an independent advocacy service that has the capacity to provide independent advocacy support for people affected by the Bill. This may mean providing funding to existing services or provide funding for new services.

5b.27 We would also recommend that each ICAS service has a named person to advise on the new legislation and good practice and to signpost individuals, families and professionals to appropriate sources of advocacy and/or undertake advocacy when there is a crisis eg life threatening situation.

5b.28 There should be a duty on professionals (social workers, medical staff, lawyers, care staff or agencies) responsible for the capacity assessment to involve an advocate where a key life changing decision needs to be taken.

5b.29 There is much to learn from the experience in Scotland where there is a requirement for local advocacy strategies to be set in every local authority area the creation of an Advocacy Safeguards Agency, which facilitates the development, evaluation, research, and dissemination of good practice around independent advocacy.

See Annex 6.2 for answers to frequently asked questions on advocacy.

5c. OMISSIONS FROM THE BILL—APPOINTEESHIPS

Appointeeships are not included in the draft Bill, but MDA believes this area of welfare provision is also highly pertinent. Appointeeships are arrangements that involve the handling of an individual’s state benefits, and are set up through the offices of the Department for Work and Pensions (DWP). There are few statistics on the number of appointeeships held; in 1996, figures provided from the Lord Chancellor’s Department suggested that 214,482 older people had such an appointeeship arrangement (many others may also use an agent to collect monies on their behalf, usually from banks, building societies or post offices).

5c.1 Appointee action is normally instigated by an application from the prospective appointee. An officer from the Department for Work and Pensions (or local authority for housing benefit) will then interview the incapacitated person to confirm that they are unable to manage their own affairs. If there is any doubt about the person's capabilities, medical evidence should be obtained. The officer will also interview the applicant to explain the responsibilities of an appointee and confirm that they are suitable to act.

5c.2 Appointees have access to all the state benefits to which someone is entitled to receive (for example, state retirement pension, Disability Living Allowance or Attendance Allowance, Income Support/Pension Credit), but not to other monies (for example, occupational pension or savings other than accrued benefits), which may currently be under the control of an EPA or receiver. Although guidance to DWP staff makes clear that if there is already an EPA or receiver then appointeeship is not appropriate, it is not unknown for an appointee and an EPA to be acting at the same time. For those whose only income is via benefits (for example, those pensioners who do not have an occupational pension) it means that the appointee has control over the whole income if the person has been assessed, on the current "one-off" occasion by DWP staff, as being mentally incapable of managing their financial affairs. This system does not accord with the principles of the draft Bill. Nor does it give people protection as there are few checks made by the DWP on appointees.

5c.3 While the MDA believes it to be very important that there is a system to enable financial decisions to be made on behalf of people dependent upon welfare benefits who lack capacity it is very concerned that the current system is potentially open to abuse and exploitation. Examples of this, taken from recent Parliamentary Ombudsman's Annual Reports are given in case studies 1 and 2, 5c.5–5.c6: p 26.

5c.4 Given that people with impaired capacity who are dependent upon welfare benefits are likely to be even more vulnerable than those with access to independent income/financial assets, as indeed potentially are their carers/family members, loss of control over their personal finances is likely to represent a major event in their life. The MDA therefore believes that appointeeships should be brought within the scope of the Bill. Decision-making as to whether someone should be subject to an appointeeship should require a proper assessment of the person's capacity in relation to their ability to make financial decisions. Appointees should be bound to the same "best interest" principles as those operating as Deputies or Donees of LPAs. A clear system of monitoring and reviewing appointeeships should be put in place to support this.

5c.5 Appointeeship Case Study 1—an example of fluctuating capacity

The Pension Service: failure to investigate fully whether to revoke an appointeeship.

5c.5.1 Mrs W complained of events from January 1998 when The Pension Service had received notification that she had been admitted to a residential nursing home for elderly mentally ill people. In June The Pension Service had accepted an application by her daughter, Mrs X, to be her appointee but had failed to investigate fully whether Mrs W remained incapable of managing her own financial affairs when that question arose in May 1999. Had they done so, it was most probable that they would have revoked the appointeeship at an earlier stage.

5c.5.2 The Ombudsman found no evidence of maladministration in the way in which The Pension Service had reached the decision for Mrs X to be Mrs W's appointee. However, they had failed to investigate fully whether Mrs W remained incapable of managing her own financial affairs. The Chief Executive wrote to Mrs W offering her personal apologies. The Pension Service paid Mrs W £317 for loss of personal expenses allowances, £1,750 for loss of disability living allowance and £340 for loss of use of those monies. They also made a consolatory payment of £200 for the gross inconvenience, embarrassment and severe distress Mrs W had suffered as a result of their actions.

5c.5.3 *Parliamentary Commissioner for Administration—Annual Report 2002–03 Chapter 3—Investigated cases—The Department for Work and Pensions and its Agencies, including the Appeals Service C1560/02.*

5c.6 Case Study 2—How Those with Appointees may be Vulnerable to Abuse

Benefits Agency: alleged improper appointment of an appointee.

5c.6.1 Mr A was unable to handle his own affairs after his discharge from hospital and the Benefits Agency (BA) appointed a neighbour to act for him, and receive his benefit. Mr A subsequently alleged that the neighbour had misappropriated the benefit. The Ombudsman criticised BA for their poor recording of the circumstances surrounding the appointment of the appointee but found no evidence that the decision had been maladministrative. The Chief Executive undertook to remind staff about the importance of good record keeping; and to consider amending the instruction on appointeeship to include a requirement to notify customers on the appointment of an appointee. He apologised for shortcomings in the handling of the case.

5c.6.2 *Parliamentary Commissioner for Administration—Annual Report 1999–2000 Chapter 3—Investigated cases—The Department for Work and Pensions and its Agencies, including the Appeals Service C176/00.*

5d. OMISSIONS FROM THE BILL—ASSESSMENT

The MDA fully supports the presumption of capacity set out in clause 3 of the draft Bill. The MDA does not wish to see the ability for any adult to make their own decisions infringed without an independent assessment of that adult's capacity. The draft Bill does not explain how assessment will work in the context of this new legislation, and we believe this omission must be addressed.

5d.1 The nature of capacity in the draft Bill is set out in clauses 1 and 2 (see MDA response on clauses 1–7). In relation to assessment, it is important to highlight that a person only lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself (MDA emphasis). The literal interpretation of this clause would require a continuous assessment of capacity each and every time that person was faced with a similar decision, but this would not be in the interests of the individual concerned, their carers or the relevant professionals.

5d.2 However, the MDA believes it is equally unacceptable for the draft Bill to erode an individual's right to make their own decisions before capacity has been accurately and independently assessed. The MDA would suggest that this would be a gross infringement of article 8 of the European Convention on Human Rights as enshrined in the Human Rights Act:

5d.3 “Everyone has the right to respect for his private and family life . . . There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.”

5d.4 The MDA believes that very few of the vulnerable adults we represent are totally unable to make their own decisions. Instead we view capacity as a sliding scale, with a person's ability to make their own decisions determined by a range of external factors, including time, physical location and the support available to them. Given that most vulnerable adults will fall between absolute capacity and an absolute inability to make decisions, the importance of assessment in underpinning the work of the draft Bill cannot be overstated.

5d.5 Given its fundamental importance, coverage of assessment in the draft Bill is alarmingly sparse. Presentations by officials have made clear that substitute decision-making should always be a last resort (clauses 2–4). Yet nowhere in the draft Bill are mechanisms set out by which the application of this principle of last resort will be monitored and by which abuses of the powers, in particular the General Authority, will be reined in.

5d.6 “Assessment” is not included within the list of expressions defined in the Bill at Clause 50, subsection (3); the MDA believes that “assessment” should be clearly defined. In clause 30, subsection (1)(a), the Lord Chancellor is required on enactment to prepare a code of practice for the guidance of persons assessing whether a person has capacity in relation to any matter. The MDA seeks clarification as to the legal status of this Code of Practice, and to any sanctions that will be applicable if the Code is breached or ignored.

5d.7 In Clause 15, subsections (a) and (b), the Court of Protection is empowered to make declarations as to whether:

- A person has or lacks capacity to make a decision specified in the declaration.
- A person has or lacks capacity to make decisions on such matters as are described in the declaration.

5d.8 In detailed discussions prior to the drafting of the Bill, officials confirmed that the functional approach to assessing capacity set out in the Making Decisions policy paper would be followed in the Bill. Making Decisions describes the functional test as, “whether the individual is able, at the time when a particular decision has to be made, to understand the nature and effect of the decision”. Making Decisions explicitly states that the functional approach is designed to prevent unnecessary intrusion into an individual's affairs and to provide the flexibility necessary for individuals whose capacity to make decisions fluctuates, such as some people with mental health problems.

5d.9 The first power of the Court of Protection, to make a declaration as to whether an individual lacks capacity to make a specific decision, is in accordance with the functional approach. However, the second power, to make a declaration as to whether an individual lacks capacity to make decisions, “on such matters as are described in the declaration” may undermine the functional approach. The MDA believes that “such matters” in this clause will allow the Court to declare that a person is unable to make a particular type of decision indefinitely. If this interpretation is correct, this power may allow the Court to decide that an individual is unable to make decisions on all matters relating to their finances, their medical treatment or their personal welfare, without regard to the particular circumstances surrounding each decision within these categories.

5d.10 The MDA would suggest that the second power should be downgraded, so that the Court of Protection may only state that an individual currently lacks capacity in relation to a particular decision, but may also express an opinion that an individual regularly experiences significant difficulty in making decisions on a particular issue and that this incapacity is therefore likely to continue. A declaration of this nature would then allow carers to claim protection under the revised General Authority proposed by the

MDA, which would now require a carer to present evidence that an independent assessment of capacity had been carried out for the person in their care. A declaration from the Court of Protection would be the highest level of evidence necessary for carers to claim protection under the General Authority, and would be appropriate where a person's capacity was contested or regularly fluctuated.

5d.11 The draft Bill sets out two sets of powers that can grant a substitute decision-maker the right to make decisions for an individual across one or more categories. The first type of powers, Lasting Powers of Attorney (LPA), relate to people who wish to plan for future incapacity (see LPA section of MDA response). For these powers, it is clearly necessary for the Donor of an LPA to have capacity at the time the LPA is made. Currently, the Bill deals with this in Schedule 1, 2, (e), which requires a person of "prescribed description" (similar to requirements around passport applications) to certify that a person has capacity. This requirement appears to contravene the presumption of capacity in clause 3 of the Bill, as the onus should be to demonstrate that an individual who wishes to make an LPA does not have capacity if any doubt exists. The MDA suggests that Schedule 1, clause 2, subsection (e) should be deleted and replaced with a requirement for a person of prescribed description to sign a statement that, in their opinion, the intended Donor of an LPA has understood the nature and purpose of the LPA. This would adhere to the functional approach to assessing capacity, as the person of prescribed description is only asked to assess the person's capacity in relation to a particular decision (the making of an LPA) at the material time.

5d.12 The second set of powers relates to individuals who are born with impaired capacity, or who have lost capacity without making an LPA. In these cases, the Court of Protection may appoint a Deputy to manage their personal welfare (including healthcare) or property and affairs, or may make a single order to resolve any dispute on a particular decision (clauses 16–20; clause 38). While the MDA broadly supports the principle of Court-appointed Deputies (see section of response on Deputies), we believe that Deputies should only be appointed when the court is satisfied that an individual regularly experiences significant difficulties in making a particular type of decision. This should require a body of expert evidence, potentially including assessments from individuals representing different professional groups. The burden of proof should be higher for Deputies than for a single order of the Court, because as an ongoing power the appointment of a Deputy contravenes the functional approach to assessing capacity. However, a similar duty should apply to single orders of the Court, where a pure functional approach to assessing capacity will be possible.

5d.13 The Bill is silent on which professional groups would be eligible to make an assessment or pronounce on an individual's capacity, for example in providing evidence before a declaration by the Court of Protection. This is particularly important as Ministers and officials rightly wish to minimise bureaucracy in the implementation of the draft Bill, and do not proposed any formal certification of incapacity as applies to medical treatment in the Scottish Act. Given this, the MDA would emphasise the importance of a holistic approach to determining capacity, with equal weight given to perspectives stemming from a social as from a medical model. Individual organisations within the MDA can produce a range of evidence that demonstrates a low level of awareness amongst medical practitioners of particular conditions, disabilities and disorders that may impair an individual's capacity.

5d.14 In addition, the draft Bill currently lacks any accessible mechanisms by which an individual may challenge a formal or informal assessment of capacity made about them. Although an individual assessed as lacking capacity can make an application to the Court of Protection to challenge any declaration made by the Court on the basis of this assessment (40, 1, a), the Bill does not explain how Ministers envisage that a person who may have a significant mental disorder can be supported to make such an application. This is another reason why the MDA believes that any individual assessed as lacking capacity who becomes the subject of the formal powers set out in the draft Bill should have the right to access independent advocacy.

5e. OMISSIONS FROM THE BILL—PUBLIC LAW PROTECTION FOR THOSE AT RISK

The MDA is disappointed that the Government has decided not to proceed with this issue as part of its review on mental capacity, as proposed in the consultation paper *Who Decides?*. We believe that the current situation is unacceptable, and the new legislation and in particular the General Authority will make the need for public law protection still more urgent. We feel that the only way to enable older people, people with a learning disability or mental health problems to receive the most appropriate help when abused is through public law protection. For example, many people with a severe learning disability or older people are unable to care for themselves or are liable to a significant risk of exploitation because of an inability to perceive or assert their rights and interests. There is a need to replace relevant sections of existing legislation such as the National Assistance Act 1948 that are inadequate and ineffective in respect of protecting people from exploitation and neglect.

5e.1 The MDA believes that social services should have the duty to investigate cases of neglect or abuse where there is evidence of significant harm or exploitation. This power would allow the local authority to review existing community care arrangements. The MDA believes that social services should be the lead agency for investigation of abuse but that social services departments should be responsible for co-ordinating responses from other agencies within a prescribed timescale.

5e.2 There is a need to maintain a balance the risk against an individual and respect for an individual's autonomy. Once it has been established that a person has the capacity to refuse the support of the local authority, that choice should be respected.

August 2003

Annex

6.1 MEMBERS OF THE MAKING DECISIONS ALLIANCE

- Add a Voice
- Action on Elder Abuse
- Age Concern England
- Alzheimer's Society
- Beth Johnson Foundation
- Carers UK
- Caring Matters (until 25 July 2003)
- Counsel and Care
- Down's Syndrome Association
- Headway
- Help the Aged
- Kent Autistic Trust
- Leonard Cheshire
- MIND
- Manic Depression Fellowship
- Mencap
- Mental Health Foundation
- National Autistic Society
- Patient Concern
- POPAN (Prevention of Professional Abuse Network)
- The Relatives & Residents Association
- RESPOND
- Rethink
- SCOPE
- Sense (The National Deafblind & Rubella Assoc)
- The Stroke Association
- Turning Point
- United Response

Annex

6.2 BACKGROUND INFORMATION ON ADVOCACY

Successive Governments have highlighted the importance of independent advocacy and showed an appreciation of the valuable role it can play in supporting people to access vital services and ensure their rights are protected. For example, the Disabled Persons Act 1986 charged local authorities with setting up a formal system of authorised representatives who could make representations about their disabled people's need for services, get a statement of assessed needs and services to be provided and make representations about this. However, this formal system was never implemented.

6.2.1 More recently, the Health and Social Care Act 2001 (part 1, section 12, clause 19A) empowers the Secretary of State "to arrange, to such extent as he considers necessary to meet all reasonable requirements, for the provision of independent advocacy services". This Act also introduced two new mechanisms to deal with health service complaints, PALS and ICAS. A similar clause exists in the draft Mental Health Act in relation to the help to be available from mental health advocates to qualifying patients and to their nominated persons.

6.2.2 In addition, numerous white papers, standards, guidance documents and reports from different Government Departments have drawn attention to the benefits advocacy can bring and emphasised the need for further development and support for such services. However, apart from the limited funding announced

in the White Paper Valuing People for services aimed at people with learning disabilities over the next three years, there has been no indication of any national Government funding or resources for independent advocacy services.

6.2.3 SOME MODELS OF ADVOCACY

Citizen Advocacy is a one-to-one ongoing partnership between a trained volunteer advocate and a person who is not in a strong position to exercise or defend their rights and is at risk of being mistreated or excluded.

Peer Advocacy is where one person advocates for another who has experience or is experiencing similar difficulties or who has similar life experiences (eg service users in a residential facility).

Professional Advocacy is where people are employed and paid within an advocacy service. This usually follows a case-work model, focussing on particular issues.

6.2.4 If someone already has a Citizen Advocate they know and trust, they should be able to use this support in this situation if they so wish and if the advocate is willing to do so rather than be required to use a paid professional advocate. Similarly, if someone wanted to have a Citizens Advocate but there are no such schemes in their area but paid professional advocates were available it would be reasonable for them to accept this as an alternative.

6.2.5 ADVOCACY CASE STUDIES

CASE STUDY 1—ADVOCACY AS A SAFEGUARD AGAINST POTENTIAL ABUSE

A man in his mid-60s has a previous history of long-term institutional admission from his 20s to late 40s. During a hospital admission a neighbour was very active in arguing for him during discharge planning and agreed to provide regular weekly support. At the meeting the gentleman did not challenge this but was still very anxious about going home. It later emerged that the neighbour had encouraged him to sell his family home to move into a bungalow near her so she could “provide support”. In return, he had invested in an extension for her property.

6.2.6 As time went on, the promised support from the neighbour never emerged. He had been unhappy with the discharge planning at the time, but had never felt comfortable saying anything in front of his neighbour. He didn’t want to upset her, as he was still hopeful that she would provide ongoing care. Due to his history of institutionalisation, he was continually scared of getting into trouble for whistle-blowing. Everyone assumed that the neighbour was advocating for him; nobody realised the neighbour wasn’t independent. Nobody actually asked the gentleman independently whether he was happy with the arrangements that had been made. An independent advocate would have asked all those important questions.

6.2.7 CASE STUDY 2

The following case study is an example of how someone’s condition and their life experience to date have both had an impact on their ability to make decisions.

6.2.7.1 A young woman with Asperger syndrome had many different placements throughout her school life and early adulthood. Her ability to make decisions was affected by these changes in surroundings. She felt was unable to control major decisions in her life, such as her placements, and, because the settings were not appropriate, her reliance on her obsessions (personal hygiene and domestic cleanliness) became more acute. The reassurance she found in her cleaning adversely affected all the other decisions she made—cleanliness was the only thing that mattered to her. As she became more settled in a more suitable supported living arrangement, her obsessions declined and she was able to engage in other activities—college, gym etc.

6.2.8 CASE STUDY 3—ADVOCACY IN THE COMMUNICATION PROCESS

A non-verbal man with autism attended an autism specific day service in a neighbouring local authority. It had always been assumed that because of his lack of language and his apparent indifference to his surroundings that he was incapable of making certain decisions. When his local authority decided that it would be cheaper for him to attend one of their own generic day centres for disabled people the day centre appointed an advocate. It soon became clear to everyone involved that he had understood what was happening and wanted to stay at his present day service. Through specific questions and his use of symbols the advocate was able to ask him about his current day service and how it helped him.

6.2.9 CASE STUDY 4—ADVOCACY ASSISTING IN THE EXPRESSION OF PREFERENCES

A man who suffered a mental breakdown at university is now paranoid about his immediate family, who are doing their best to help him. However, he sees any support they suggest as oppressive and detrimental to his interests. He is very intelligent and can communicate well, but his views are distorted through his delusional beliefs. An independent advocate is needed to help him express his preferences to enable decisions to be made in his best interests.

6.2.10 CASE STUDY 5—ADVOCACY IN THE PROCESS OF GAINING CONSENT

A young man with autism and very little language needed a hernia operation and was in a great deal of pain. Because of his autism he hadn't alerted anybody to the pain he was suffering. Staff began to notice his discomfort and he went to a doctor. He lived in an autism specific residential service and the staff, his parents, his psychologist and surgeon agreed he needed the operation. However without the use of an advocate it was agreed that consent could not be assumed. The advocate was able to explain impartially the consequences of an operation. Following access to an advocate he gave consent and the operation was successful.

6.2.11 CASE STUDY 6—ADVOCACY IN CHALLENGING PROFESSIONAL DECISIONS

A lady in her mid 90s was living alone in warden accommodation. She was physically ill but refused on several occasions to go into hospital. It was unknown how serious her illness was due to lack of tests (which could only be done in the hospital)—it may have been a minor blockage that could be easily rectified, but it could also have been something much more sinister. Due to past history the lady was adamant she did not want to leave her home as she was very clear that she wanted to die in her own home. She was aware that she may be shortening her life by this decision but for her the potential benefits of a move into hospital did not outweigh the fear of going there. The GP became very anxious about this and instigated a Mental Health Act assessment, the GP tried to argue there were questions over the lady's capacity but it seemed much more to be a case of "covering the back" by the GP.

6.2.11.1 The lady was very traumatised by the experience of many strangers entering her home and asking very personal questions. There needed to be someone in this process very clearly advocating for her wishes to stay at home, as her wishes seemed to be totally lost in this process. The concern would be that a GP under the new system would act under the General Authority and remove her into hospital, as the lady herself could express her wishes if given the time and space and when asked appropriately but was too weak to really challenge anyone. An advocate would have clearly been able to challenge the GP's concerns and any "medical" decisions that he made.

6.2.12 CASE STUDY 7—ADVOCACY IN FAMILY DISPUTES

A man's health was deteriorating; and his insight and ability to communicate were severely diminished. There was an on-going dispute between his sister and father and his wife when he became ill, which resulted in a long battle to register an EPA. The family said they were quite happy for his wife to handle all financial and business matters with the EPA not being registered. However, the family then started to take him to meet with solicitors and clerks, seeking revocation of the EPA when he visited them, causing much friction. An independent advocate may have helped to establish and communicate his views.

6.2.13 FREQUENTLY ASKED QUESTIONS ON ADVOCACY

6.2.13.1 Q. *How can you advocate for someone whose views on the particular issue can't be established?*

A. You can build up a picture of a person's views and preferences from their behaviours and the way they react to different things. From that, it is possible to work out what they may prefer to happen and what makes them happy. It is however very important for advocates to make it clear when it is not possible to ascertain someone's wishes and feelings.

6.2.13.2 Q. *How can you get the views of preferences of people who are mentally incapable?*

A. Mental capacity isn't a black and white issue. Someone may be capable of making some decisions and not others, or may not be capable of making many decisions but could be able to express views or preferences that can help guide the actions of the substitute decision-maker. An independent advocate can help explain to someone in a way they are more likely to understand what the decision is about so that as far as possible their views are considered.

6.2.13.3 Q. How would you ensure advocate is independent and accountable?

A. The independence of the advocate is important to the success of the advocacy. Work needs to be done by organisations providing advocacy to establish how advocates can guarantee independence and accountability for the individual. But we need to make sure that the possibility of informal advocacy is not removed through any formal process of ensuring independence and accountability.

6.2.13.4 Q. Who should be responsible for providing and / or resourcing this advocacy input?

A. Central Government should fund the provision of independent advocacy support needed to make the commitment in the Bill to a presumption of capacity a reality.

6.2.13.5 Q. How much would this cost?

A. No accurate figures are available. However, the MDA believes that every local authority area should have an independent advocacy service that is able to support people who are affected by the Bill. For some areas, this will be new provision. For others, existing services would need to be enhanced. It should also be borne in mind, however, that many of recommendations are about providing access to advocacy for those who do not have alternatives. Most people will probably continue to use informal advocates (family, friends, and neighbours) with no substantial cost implications.

Annex

6.3 MDA COMMENTARY ON MENTAL CAPACITY LEGISLATION IN OTHER COUNTRIES

Mental capacity legislation has been the subject of debate and legislative change around the world over the past 20 years. Many countries have made changes to their laws to ensure that they deliver the necessary safeguards for citizens who lack capacity to consent. An ageing population, advances in medical technology enabling people with severe disabilities to live longer, and the move from institutionalisation to community-based living, were cited as the main reasons for reform. These are all issues that are relevant to England, Wales and Northern Ireland.

This paper examines mental capacity legislation in Scotland, Australia and Canada.

6.3.1 SCOTLAND***The Adults with Incapacity (Scotland) Act 2000***

In March 2000, the Scottish Parliament passed this act, recognising that the existing law was failing to meet the needs of adults unable to make decisions for themselves. The Scottish Law Commission produced a report in 1995 on the subject and, after extensive consultation, the Adults with Incapacity Act was passed in May 2000.

6.3.1.1 Mental capacity legislation takes a functional approach to determining capacity. So, the act makes an assumption that individuals will be able to make their own decision unless it is proved that they are unable to do so. The act states clearly that interventions in the affairs of adults who lack capacity must be in the best interests of that adult; and that the guardian (a spouse, nearest relative, and so on) has a General Authority to act reasonably on day-to-day decisions. The Act creates a new offence for an appointed guardian neglecting his/her duties or failing to act for the benefit of the person who lacks capacity to consent.

6.3.1.2 Under the Act, several agencies supervise those who take decisions on behalf of the adult, ensuring those decisions are in the person's best interests. These agencies include:

- the Public Guardian, which has a supervisory role and keeps registers of attorneys, people who can access an adult's funds, guardians and intervention orders;
- local authorities, which can look after the welfare of adults who lack capacity in instances where no guardian can be found (other local authority roles under the Act include investigating circumstances where the personal welfare of an adult is at risk, providing information and advice to those exercising welfare powers and supervising attorneys and guardians); and
- the Mental Welfare Commission, which protects the interests of adults who lack capacity as a result of mental disorder.

6.3.1.3 Under the Act, the main ways that other people can make decisions for an adult who lacks capacity are as follows:

- Power of Attorney

Individuals can arrange for their welfare to be safeguarded and their affairs to be managed properly. They can do this by giving another person (who could be a relative, carer, professional person or trusted friend) power of attorney to look after some or all of their property and financial affairs and/or to make specified decisions about their personal welfare, including medical treatment.

— Intervention and guardianship orders

Individuals can apply to their local sheriff court for an intervention order where a one-off decision or short-term help is required, or a guardianship order, which may be more appropriate in cases where there is a need for the continuous management of affairs or the safeguarding of welfare. Any person claiming an interest in the adult's affairs, or a local authority may make applications for intervention and guardianship orders.

— Medical treatment and research

The act allows treatment to be given to safeguard or promote the physical or mental health of an adult unable to consent. Where there is disagreement a second medical opinion can be sought. Medical practitioners have to consult close relatives before administering medical treatment. Cases can also be referred to the Court of Session in certain circumstances. The act also permits research involving an adult incapable of giving consent, but only under strict guidelines.

— Access to the adult's funds

Individuals (normally relatives or carers) can apply to the Public Guardian to gain access to the funds. Authorised housing and care services can also manage a limited amount of the funds and property of residents.

6.3.2 AUSTRALIA

All the Australian States introduced mental capacity legislation between the late 1980s and 1990s. The principal model is the Guardianship and Administration Board Act 1986, in Victoria (recently amended in 1999). Legislation covering different states takes the functional approach to determining capacity. This paper examines South Australia's Guardianship and Administration Act 1993 as an example of the approach used by other states.

6.3.2.1 *The Guardianship and Administration Act 1993—South Australia*

The Guardianship and Administration Act 1993 came into operation in 1995. This set the Guardianship Board, which is responsible for applying the new law, the task of setting out a number of orders. It is assumed that close relatives will make day-to-day decisions, but the Act encourages those who may lack capacity in the future to appoint a guardian. However, guardians can only make welfare and medical decisions on someone's behalf. The act creates a new offence for an appointed guardian neglecting his/her duties or failing to act for the benefit of the person who lacks capacity to consent.

6.3.2.2 *Administration Orders*

In terms of welfare and financial affairs, the Guardianship Board may appoint an administrator to look after such affairs. The following can be appointed to act as an administrator:

- The Public Trustee.
- A trustee company under the Trustee Companies Act 1988.
- A relative appointed by the Board.

6.3.2.3 *Medical decisions*

There are two laws that deal with the issue of who has the legal authority to consent to medical and dental treatment:

- Consent to Medical Treatment and Palliative Care Act 1995.
- Guardianship and Administration Act 1993.

6.3.2.4 If a person has not appointed a "Medical Agent", or has not made an "Anticipatory Direction" (a living will) under the Consent to Medical Treatment and Palliative Care Act 1995, and mental capacity is lost, then consent to medical or dental treatment for a person with a mental incapacity must be sought from the following:

- (a) the guardian appointed by a person, prior to mental incapacity, to make medical decisions;
- (b) the guardian appointed by the Guardianship Board under a Guardianship Order. The written order will specify the areas in which the guardian is empowered to make decisions;
- (c) where there is no guardian or enduring guardian, specified relatives can give consent, including a spouse, a parent, a sister or brother aged 18 years or older, a daughter or son of aged 18 years or older.

6.3.2.5 In terms of prescribed treatment such as an operation, where a person is unable to give their consent, the Guardianship Board is the only authority that can give consent. The Guardianship Board is governed by a set of criteria when making decisions about such a treatment or procedure.

6.3.2.6 The Office of the Public Advocate has also been set up as a “watchdog” with the responsibility of educating the public on issues relating to disability and promoting the interests of people who lack capacity to consent, and in some instances, their carers.

6.3.3 CANADA

Adult guardianship legislation

The situation in Canada is similar to Australia’s in the way that each province has its own legislation. Until recently, mental capacity legislation varied considerably from province to province. There were two main approaches adopted. The traditional system regarded incompetence as absolute (eg Ontario’s Mental Incompetence Act 1980). This means that legal rights, possessions and decision-making power of the person lacking capacity to consent are transferred to another once the court makes a decision that the person lacks the capacity to consent.

6.3.3.1 This approach was heavily criticised by disability organisations as being paternalistic and open to abuse. Major reform took place in the early 1990’s (see Ontario case study).

6.3.3.2 The second approach, adopted in Alberta (the Dependent Adults Act 1976), was one of the earliest attempts to adopt a more functional approach to mental capacity.

6.3.3.3 Ontario—towards reform

In 1992, Ontario abolished its mental incompetence guardianship regime and enacted three new legislations: the Consent to Treatment Act 1992, the Advocacy Act 1992² and the Substitute Decision Act 1992. This legal reform promoted the autonomy of those who lack capacity to consent, and prevented unnecessary legal intervention in their lives. The Act states clearly that interventions in the affairs of adults who lack capacity must be in their best interests. People will be presumed to be able to make their own decisions, unless it is proved otherwise. In all the areas of decision-making, the Act makes clear the need to encourage the individual to participate as fully as possible in any decision affecting him/her. The appointed guardian has a General Authority to act reasonably. As with the legislation in Scotland and Australia described above, the act creates a new offence for an appointed guardian neglecting his/her duties or failing to act for the benefit of the person who lacks capacity to consent.

6.3.3.4 Individuals can arrange for their welfare to be safeguarded and their affairs to be managed properly, by giving another person (who could be a relative, carer, professional person or trusted friend) power of attorney. These include decisions about their property and financial affairs and/or to make specified decisions about their personal welfare, including medical treatment.

6.3.3.5 Finally, the Health Care Consent Act has created a simple procedure that recognises the social position of family members as natural substitute decision-makers. It provides the legal framework for carers to appeal against medical decisions. It should be noted, however, that if the patient has granted the power of attorney for personal care or if a guardian has been appointed, then the attorney becomes the substitute decision-maker and other family members lose their automatic status.

6.3.3.6 Ontario’s legislation has also established the Office of the Public Guardian and Trustee to provide a number of services. Some of these include:

- Property Guardianship

This service manages the financial affairs of individuals who lack capacity to consent, when there is no one else who is able, willing and appropriate to provide this service for them. The office may be appointed as guardian of property by a doctor in a psychiatric facility, a designated capacity assessor, or the court.

- Personal Care Guardianship

The Personal Care Guardianship is occasionally appointed as guardian of the person to make personal care decisions for a mentally incapable adult, if this is necessary to protect the person from serious personal harm. Only a court can make these appointments. As guardian of the person, it is the office’s responsibility to make decisions about things like custody, safety and housing.

- Decisions about Treatment and Admission to long-term care

This service is responsible for making decisions about medical treatment and admission to long-term care for those who are mentally incapable of doing so when there is no one else, such as a family member, willing and able to provide this service.

² In 1996, the Advocacy Act was repealed and the Consent to Treatment Act was replaced by the Health Care Consent Act. This was done under the Advocacy, Consent and Substitute Decision Statute Law Amendment Act 1996.

Witnesses: **Mr Clive Evers**, Alzheimer's Society, **Mr Simon Foster**, Mind, **Mr Roger Goss**, Patient Concern, **Dr Andrew McCulloch**, Mental Health Foundation, **Ms Pauline Thompson**, Age Concern, and **Ms Kathryn Willmington**, Help the Aged, Making Decisions Alliance, examined.

Q92 Chairman: Thank you all for your written evidence, which was very helpful, and for taking time to attend. The session is open to the public and it may be recorded for broadcasting. There is a verbatim transcript of the evidence which will be published with the Committee's report and you will be asked to check the text for accuracy, although the unedited text is put on the parliamentary website. If there is a division, I will have to adjourn the Committee for about 10 or 12 minutes. I think there should be a note of the interests of the members which are relevant to this inquiry. Representatives of the departmental and Bill team are present as observers. We are not required to report on the White Paper on mental incapacity; we are asked to report on the draft Bill and that is why the questions have been structured around the structure of the Bill. Perhaps you would like to introduce yourselves and if you wish to make a short, opening statement you are free to do so.

Dr McCulloch: I am Andrew McCulloch. I am the chief executive of the Mental Health Foundation which is a charity working with people of all ages with mental health problems and also people with learning disabilities. I would like to say how important this Bill and this issue is for the service users, carers and donors to our organisation. We are aware of various issues coming up, including people who are not being cared for properly, whose wishes are not taken into account in terms of their practical, daily living and we are also aware of instances where people are subject to abuse or have had their assets taken away from them by others. It is a very important issue.

Ms Thompson: I am Pauline Thompson. I am a policy officer at Age Concern with specific reference to community care finance. My interest here is about the financial issue and how we can use this Bill to learn from what has happened and move on from EPAs where, when they work well, they work tremendously well but, when they go wrong, they go very wrong; and how to have the right checks and balances and how people who have lost capacity can get redress if anything does go wrong.

Mr Goss: My Lords, ladies and gentlemen, good afternoon. I never thought I would get the chance to say that. I am Roger Goss, co-director of Patient Concern. We are about gently nudging clinical culture away from its traditional mode of "we inform; you consent" towards a more patient friendly "we advise; you decide", in the case of those people who want to exercise that judgment. I have been involved with the subject of advance statements and directives for about ten years. I made an oral presentation to the then LCD Minister in response to the Who Decides? Law Commission report. As son of the manse, I am very conscious of how sensitive the issue of refusal of treatment is. I would only comment that the only difference between groups opposed to this legislation and ourselves is that those groups feel they have a duty to enforce their convictions on everyone; whereas we believe everyone should have a chance to make their own

decisions. If it would be of any value to you at some stage, Patient Concern specifically would like to suggest a couple of amendments that we think would improve the Bill.

Ms Willmington: I am here representing Help the Aged as a policy officer. We estimate that at least one million older people are directly affected by issues of incapacity and you can easily double that when you take into account carers and other professionals. We strongly support the implementation of this Bill with certain additional amendments, as suggested.

Mr Foster: My name is Simon Foster. I am principal solicitor at Mind, the mental health charity, so I have particular interest in the legal implications. The particular focus that we have is around people with fluctuating capacity where there are enormous issues raised for people who have capacity. If they lose it, they regain it again and the question is how to balance their own right to autonomy, to make their own decisions against the need for protection, where required.

Mr Evers: Clive Evers, director of information and education at the Alzheimer's Society, which is a leading UK care and research charity for all forms of dementia. We are a membership organisation with some 25,000 members who have written to us over the last ten years about many issues around capacity. It is important to note that there are some 700,000 people with dementia in the UK. Most of them are elderly but 18,500 are below the age of 65. People with dementia are living longer. People are living for up to 20 years. Carers continue to be the front line for looking after people with dementia and this Bill is very important because it will provide justification for the decisions that they have to take on a daily basis, but also important protection for people with dementia as well.

Q93 Chairman: I think you have seen the questions. If there are any questions that we do not reach or if there are any suggestions you wish to make to us in writing after the session, you are of course free to do so. Under the heading "Best Interest", does the proposed check list on best interest strike a balance between supporting the autonomy of the person with incapacity and providing them with protection and is the suggestion from the MDA that the "best interest" should be replaced with "best personal interest"? Is that just a question of semantics or is there something much more important beyond that?

Ms Willmington: One of our concerns about best interest is the issue that the person reasonably believes they lack capacity. Anybody can act in somebody's best interest if they really believe that person lacks capacity. We are concerned that this tips the balance in the wrong way. We feel it gives a presumption of incapacity and that goes contrary to the stated aims and principles of the Bill which have a presumption of capacity. It gives people the opportunity to say, "We presume that person . . .", so I think we feel we would like to see that either removed from the Bill or amended to have sufficient safeguards. We felt that there should be included a

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reasonable expectation about a decision over whether the person is going to recover and be included in the check list of best interest. That is part of the decision in terms of safeguarding best interest. Our main concern about best interest is the conflict. You can get a medical best interest; you can get a financial best interest or a welfare best interest. This is why we specifically put in the point about having the best personal interest as some way of trying to resolve that debate and steer people when they are trying to resolve those conflicts about what is somebody's best interest, to be able to say it is what is best for that particular person, whether their financial, medical or welfare best interest.

Q94 Chairman: The intention is to treat each person as an individual so you would always be thinking about a best personal interest. Is it not just semantics?

Ms Willmington: It is about particular decisions where a doctor, for example, says, "I think I know what this person's best interest is." Somebody else says, "I think I know what this person's best interest is." It is about trying to make sure that the focus is shifted away from other people's interpretation of best interest towards their interpretation of what they perceive of that person. It is important that that word be included because of that.

Mr Evers: For example, the importance of personal best interest would be in relation to somebody with Alzheimer's disease in a hospital setting or care home setting, where they may well be prescribed neuroleptics to control their behaviour. That may be in the best interests of other residents in that hospital or care home setting, but it is certainly not necessarily in the best interests of the patient.

Q95 Lord Rix: Does the draft Bill provide sufficient protection for the best interests of people with impaired decision making, people for instance with a learning disability, who then become more incapacitated by mental illness, dementia, age? Is there sufficient flexibility for changing capacity in the Bill at the moment?

Mr Foster: That is a very good question and quite difficult to answer until it is put into practice. Like any check list of best interests, the question is of trying to anticipate, trying to build in all the different factors, starting from the point of view of supporting the individual to make those decisions that that person can make, which must be the presumption. Where somebody has impaired decision making, they are not incapable of making any decisions. They are capable of making some and it is a question of trying to help and encourage people to make the decisions they can and then only looking at substitute decision making for those areas where the person is not capable. I would add the word "necessary" on the decision making where a decision has to be made, at clause 4, paragraph one. The Alliance is very keen on the whole on the idea of the general authority but subject to proper safeguards and checks, in order to enable that flexibility, where somebody's capacity fluctuates, where somebody is

impaired in the first place and becomes additionally impaired as time goes on, who will have good days and bad days.

Q96 Mr Burstow: Can you give any examples from other pieces of law or judgments by the court where best personal interest has been defined? What would be the additional test that would enable you to distinguish it from best interest? In relation to the oral evidence we had last week, I was not here but I have read some of the unamended transcript. There was a question there about the Scottish experience of having a list of principles at the beginning of the legislation. I wondered why that was not something which you had looked at and, if you have looked at it, why you think that best interest is more preferable than best personal interest.

Mr Evers: We have looked at the Scottish legislation quite carefully. Much of it we support. In particular, we draw attention to the least restrictive option. That is something that could easily be added, so we are aware of that.

Ms Willmington: We still prefer the concept of best interest or best personal interest than what exists.

Q97 Baroness Fookes: Could I query⁷ this illustration you gave that maybe the best interests could be served in the home where the person might make a nuisance of themselves rather than the person themselves? I would have thought the Bill made it abundantly clear that the decision must be made in the person's best interest. How possibly can you substitute the home for that? It seems to me it is already absolutely clear.

Mr Foster: I used to be a child care lawyer and the wording of the Children Act is rather different language. It talks about the welfare of the child being the paramount consideration. Once you start talking about best interest, it is very tempting to say it is obviously in the best interest of that person that there is harmony in the home, that the neighbours are happy etc. It is very easy to lose the focus on the individual who is being safeguarded, rather than the smooth running of the home, which of course is beneficial to the interests of the person as well. Trying to get that balance and trying to put the focus very firmly on the individual and how that then squares with the other residents etc. is the point the Alliance is trying to bring out.

Baroness Fookes: I am not convinced.

Q98 Baroness McIntosh of Hudnall: I wanted to go back to the relationship to the Scottish legislation because it feels to me as though best interest is a volatile concept and we keep coming back to this issue. The Scottish legislation provides that there has to be a demonstrable benefit to the individual flowing from any decision that is taken on his or her behalf. You presumably considered that as an alternative. Can you tell us why you continue to believe that best interest, albeit amended, is the right language, as opposed to any other?

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Ms Willmington: It is the devil and the deep blue sea. I am not sure we felt that there was one magic solution. We felt this was possibly the best. We were happy that this did reflect the ideas and underlying principles. I know there is concern about how paternalistic it sounds and that is one of the reasons why we felt we should add the best personal interest as a way of trying to counter that.

Q99 Chairman: Which of the organisations works on a UK basis as opposed to only in England? Are any of your organisations experiencing the Scottish Act?

Dr McCulloch: We do work on a UK basis. I have not had many reports yet of people experiencing the Scottish Act. Its coverage is not going very far in terms of depth and therefore one would not necessarily expect that at this stage. The proposal that we have here would be more all embracing in terms of day to day practice.

Chairman: As we go through the questions, if there is anything which occurs to you where the experience in Scotland would be helpful, perhaps you could tell us.

Q100 Baroness Barker: Could I probe a little more your exception to the phrase “reasonable belief”? I agree that it is a phrase which can be interpreted in two ways. One is an excuse but one is a requirement to demonstrate the basis upon which somebody believes something to be in somebody’s best interest. Why do you take a negative view of that phrase?

Ms Willmington: Because of the first interpretation and the concern that it would be used and we are concerned that people would interpret it in a way in which they could justify actions. It gives them more ability to flexibly interpret it. The problem is that capacity is only ever a question of judgment and we were concerned that because it is such a difficult thing to measure it is always a question of subjective judgment and we were concerned that, by leaving it open that way, it gave people the opportunity to interpret it very flexibly.

The Committee suspended for a division.

Q101 Baroness Fookes: You advise that the phrase that a person reasonably believes that a person lacks capacity should be removed from the Bill. What protection would there then be for somebody acting in the best interest, say, in an accident and emergency department or some other immediate emergency?

Ms Willmington: We thought about that issue and our feeling is that whoever was acting in that situation, if they were challenged, we would want them to be able to show what steps they took to ascertain the person’s capacity, opinions, views, best personal interest etc., given the bounds of what would be reasonable to expect in that situation and also the necessity and emergency of that situation so there would be protection for that person in that situation. We would not be entirely opposed to the idea of it being amended. We are looking with the

eyes of the general public as to how they would interpret that phrase, rather than it being in a person’s own judgment, if they have evidence of an objective judgment, for example. I think we are completely aware that in situations of emergency and necessity people are going to have to be able to act. There will always be that justification and reason because people have to act sometimes very quickly.

Q102 Baroness Fookes: You will surely need in that case to present us with some form of wording because I cannot quite see what would replace this, bearing in mind that I think “reasonably” does offer protection and indeed a restriction.

Mr Foster: The difficulty that we have had with the phrase “reasonable belief” which is something that lawyers are used to is that that phrase is not necessarily so readily available to people who are not used to deciphering the language. It is very tempting to say, “I believe that I am a reasonable person and therefore it is a reasonable thing to do.” It may be a semantic point but we are thinking, in terms of a form of words, about a belief based upon objective evidence or something along those lines. It is tempting to say this could be put into a code of practice. I think we are all agreed that a code will be terribly important for the nuts and bolts. I believe that we are saying this needs to be much clearer on the face of the Bill, to bring out the fact that it is not simply the subjective view of the individual; it is based upon something objective.

Q103 Baroness Fookes: It will be others, will it not, who will judge whether the individual was acting reasonably?

Ms Willmington: We are concerned that people do not use it to justify actions. We are trying to make sure that people interpret this Bill correctly and they do not use it to justify doing things that they should not.

Q104 Mr Burstow: I would like to move to clause 6, the general authority, and the issues that arise out of that. We have had in submissions reference to concerns by self-advocacy groups who are worried that it is going to be difficult for people to complain if they disagree with the choice that has been made on their behalf under the general authority. We were wondering if you could say a little more about what mechanisms could be included on the face of the Bill that would enable people to challenge decisions that have been made under the general authority.

Dr McCulloch: We welcome the principle of the general authority but at the moment, as it is couched in the Bill, it is something of a *carte blanche* to people, particularly in situations where they are exercising it on a continuing basis, rather than the emergency situation we have just been discussing. We would suggest that there are a number of measures that could be taken to ensure that the individuals’ wishes are given more weight, so that the individual has more opportunity to challenge that authority if they feel they need to. One of them

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would be to have some sort of competent authority to which a person could go, or to which a concerned person could go to trigger an assessment. It might be appropriate for that authority to be a social services authority, but that is a matter for discussion. It is also important that the mechanisms set within this Bill are embedded within the real care processes that exist out there at the moment, processes like the care programme approach, the care planning, multidisciplinary team meetings and the like. Patient records, whether they are written or electronic, should be used to enable these processes to be kept track of. There are a couple of other mechanisms which would be extremely useful. One is that we are advocating the use of advance statements and that would enable someone to give a clearer, positive expression of a particular wish that could be taken account of. We are also particularly keen on the development of advocacy services. They would be very relevant in this particular situation, where someone feels that perhaps the general authority has not been exercised properly. They may not even have the words to express that in a bureaucratic or legalistic way. If they have an understanding lay advocate that they can turn to, that person can help them to access either the statutory mechanisms or the mechanisms within the NHS or local authorities to raise that issue and ask for an assessment or trigger some sort of complaints mechanism. It is about thinking through what sort of processes are needed to support the individual in the real world. I do not think we can have a general assessment of absolutely everybody by a local authority. The numbers are just too big. We have to think through what a realistic mechanism might be.

Ms Willmington: Our vision would be one in which the general authority was placed within the existing mechanisms described so it would be discussed and reviewed regularly. The important thing about that is it is not left to the closed relationship between the carer and the individual; it is discussed as part of a multidisciplinary team meeting. People discuss their feelings about whether it is appropriate and whether they think it is being used appropriately. Obviously it is not going to be relevant for everybody because not every single person who has capacity problems is part of the single assessment process. Unfortunately, we do not have the answer to that but we feel it is one way of trying to embed it in the existing mechanisms.

Q105 Mr Burstow: Picking up on the point about this being a question of real processes in the real world, one aspect of that might be the current no secrets guidance from the Department of Health. Would you be recommending that that would need to be redrafted and, as it stands, in terms of its implementation, does it provide an adequate framework in which the real world processes can be relied upon to pick up this sort of abuse?

Ms Willmington: There needs to be linkage specifically with the no secrets. One of the things we suggested was a duty upon local authorities to monitor general authorities. That would be a very easy way of linking the two things.

Ms Thompson: It is a financial point but it is an important point that we have a large number of people in care homes who, because of an accident of having more than £19,500, are funding their own care although they might lack mental capacity. On the whole, the local authority is very loath to make the arrangements for them. Therefore they do not come under care management and the Bill might help to strengthen this, if one did have that sort of linkage. There should be a duty on local authorities to keep a weather eye on some of these people who are in care homes. I understand through the National Care Standards Commission that there is an issue here. We have a large number of people who might lack mental capacity but, because the receiver has made the care arrangements with the home, they are no longer under local authority care management because they just happen to have more than £19,500.

Q106 Baroness Fookes: I am still worried about those who are not living in care homes or any sort of residential institution. What about the person in a private home whose only contact perhaps is with a carer with the general authority with whom they disagree or want to make a complaint about? How on earth do they get to any outside body, including an advocate?

Ms Willmington: That is when it comes down to public education. I think it is important that those mechanisms exist. I am a very strong advocate for advocacy, particularly for that scenario. In a perfect world we would be able to reach every single person, but we are living in the real world and all we can say is that it is important to have as many mechanisms as possible to try and catch as many people as possible.

Q107 Baroness Fookes: Supposing you had a concerned neighbour who was not a carer but who was worried about what was going on next door. How would he or she tap into the system?

Mr Evers: There are systems at the moment to do that through the no secrets guidance. Social services have a clear responsibility for the protection of individuals at home, particularly elderly people. Through that mechanism an alert could be made through social services and the system would pick up through the case review that we have already discussed.

Mr Foster: My sympathy is with you in the way you phrase the question. I can only speak from my perspective but we are terribly concerned about those people who have lost capacity and have regained it. They are outraged at what has been done supposedly on their behalf. I do not wish to speak for the Alliance but Mind would be very pleased to see ultimately some sort of resource to a court, where appropriate. How that would work in such a way that would balance the legal flexibility and freedom of the carers to make proper decisions while not exceeding their brief is an enormously difficult matter and one that we would be happy to give a view on at some later stage, if appropriate.

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Q108 Mrs Humble: Returning to your comment about any system being placed in the real world, one reality now is that many especially older people, people with disabilities, have direct payments and employ their own carers directly. People with their own resources have been able to do that for many years. Given that the relationship of the carer to the individual being cared for is one of employer and employee, how do you see that fitting into these proposals? Do you have any comments on that situation?

Ms Willmington: One of my understandings is that somebody who at the moment experiences direct payments has to have full capacity. What could happen is that a carer or somebody else in the family could go through the direct payments process on their behalf. My sense is that that probably would not be a direct problem in terms of the Bill. If somebody who lacked capacity did have direct payments, there would probably be at least one other significant person who would, I imagine, have one of the mechanisms within this Bill that they would be acting under.

Q109 Mrs Humble: That would also cover somebody who might have capacity when they started in the system but who may lose capacity later and they could then enter into arrangements that are elsewhere in this Bill?

Ms Willmington: The reality with direct payments is that although social services are not directly providing the service, they still have a duty to review. At some point they would be looking at the mechanisms within the Bill.

Ms Thompson: You have to have the capacity to manage direct payments yourself or with help. Social services are still responsible for the care that that person gets and because they are making payments for that person they have to make sure they are being spent giving them the care they need.

Q110 Baroness Knight of Collingtree: Ms Willmington said something a short while ago which I thought displayed a very touching faith in the ability of local authorities. She said that local authorities could be made to oversee the decisions, as it were. I do not know whether I am getting cynical but in my experience in recent years it has been increasingly difficult for the local authorities to deal competently with all the care problems they have with children and certainly with elderly people in their areas. I cannot quite see how it is going to be feasible to put another load on them and how would you think they would be able to cope if they had one?

Ms Willmington: They will probably give evidence on their own behalf. My belief is that they are dealing with the problems that the lack of this Bill causes. From their point of view, they would probably be very relieved that for the first time there are mechanisms they can use to help them do their jobs professionally. I would hope that they would positively welcome this as a way to help them ease their workload in a very positive way.

Ms Thompson: Local authorities already have the lead on No Secrets, so they should have the mechanisms set up. We would like to see more clearly how they are working.

Q111 Baroness Knight of Collingtree: There is nothing else you would feel that they would have to have at their fingertips in order for them to take on these extra duties?

Mr Evers: They would certainly need to have a clear understanding of the mechanism of this Bill. There is a significant public and professional education job to do on how this will work and we may come to that later on, but that is crucial.

Q112 Lord Rix: This question really should be addressed to the witnesses tomorrow but people with learning disability and self-advocate groups are very suspicious of the professionals representing them, the parents representing them, the carers representing them and this Bill in particular. Does the same apply to self-advocates with mental illness, say?

Dr McCulloch: I think it does. I fear that that is partly due to the context of this Bill, coming as it does after the proposals on mental health which have been greeted with almost universal dismay by patients, users, professionals and voluntary organisations. That is rather an unfortunate context, where there has been an opportunity to debate it in detail and where service users who are working with the Mental Health Foundation, some of whom are particularly interested in the issue of advance statements, see this Bill as an opportunity to enhance their rights and enhance the ability for self-representation. Some mention of advocacy on the face of the Bill and a commitment of resources by government for advocacy would go a massive way to reassure service users that government is serious about enhancing people's rights, rather than taking rights away. I think the door is very much more open on the Incapacity Bill than it is on the Mental Health Bill. There is a need to put some clear blue water between what is happening here and a debate on mental health. Support for advocacy would be a very strong way to do that. I do not know if that makes any sense.

Q113 Lord Rix: Absolutely. What are the chances, do you think, of us increasing the availability of advocacy or self-advocacy?

Ms Willmington: It is something that I would like to see happen. Everybody is campaigning for it. I do not think there is a need for this to be separate from advocacy generally. Obviously people will need special training but there is not a need for a specialist advocacy service. If possible, we would like to see local authorities having a duty to provide an independent advocacy service as a right. Not all local authorities would have to start from scratch with that. Some of them would be able to use existing advocacy services. It is not as huge as some people perceive. You may think I am going back to semantics again but another thing is the very title of

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the Bill. We think people would feel much more positively about it if it was the Mental Capacity Bill, because that seems to reflect the principle of supporting decisions, rather than the Mental Incapacity Bill, which seems to be more about presuming incapacity.

Q114 Chairman: Should local authorities be provided with specific powers to investigate allegations of abuse and to provide protection for vulnerable people, which I believe was originally suggested in the Law Commission's report?

Mr Foster: Yes.

Q115 Mr Burstow: I wanted to pick up on the point about some of the ways in which the Bill talks about people who lack capacity and some of the assumptions. Could you develop a little the point made in the MDA submission about, rather than assuming that the general authority is triggered, that it is just there and available to be used, that instead it should be triggered in some way? Can you explain to us how you would envisage it being triggered and what the mechanism would be to enable that to happen? Are there any other restrictions that you feel should be placed on the general authority?

Ms Willmington: We feel the triggering should be part of a case conference or review discussion. Rather than one person making that decision, it is recorded in a multidisciplinary way and that gives the opportunity for people to challenge it and to be aware that it is happening. We feel quite strongly that certain decisions are not appropriate to be made under the general authority, really serious, life changing decisions. There are not sufficient safeguards within this. One decision can potentially change somebody's life. We felt decisions about where you live, about significant changes to your care, financial decisions of any magnitude should be excluded from the general authority. Carers and family friends should not be allowed to consent to medical treatment. Doctors should be able to do that but with additional safeguards. If they are consenting to medical treatment, it should be part of a clinical decision and they should have a duty to consult families and friends. If they cannot get consent doing that, they should have recourse to go for a second medical opinion and, if not, there should be a case for protection.

Q116 Mr Burstow: In the scenario you have just described, some might be concerned that one of the consequences is that in situations of urgency and emergency decisions do not get taken at the speed necessary to save life.

Ms Willmington: I am very pleased that you have brought up that point. I meant to add that we felt there would be a clause so that in emergencies people could act and they would not need to go through that process. Obviously there would have to be a balance between the emergency of the situation and whether that would be appropriate.

Mr Foster: What I am picking up is that the honourable members of the Committee are as concerned about the general authority as we are. On the one hand, we think it is a very valuable thing. Frankly, people have been making decisions on behalf of somebody without capacity without any legal framework or justification going back as far as whenever. At least it is regularised and people should know what the limits are. On the other hand, it is enormously difficult to regulate and preserve the flexibility that is necessary. I think the questions that have been raised are very serious and very important and valuable. As I think you were suggesting, an awful lot of people are incapacitated. A decision needs to be taken rather quickly: here is somebody who is not currently in contact with the authorities of whatever sort and it cannot reasonably be left. It is highly desirable that it should be triggered by a conference, wherever possible. Then it can be looked at in a regularised way, rather than letting somebody do their own thing.

Q117 Mr Burstow: With regard to workload and the capacity of the authorities to take this on, in terms of case conferences, you are presumably describing an additional task, because there will be many cases where decisions have to be made under the general authority that would not have ever come to a case conference under current arrangements. Do you really think there is the additional capacity? I know from my own constituency mail bag that case conferences get cancelled or never quite happen or not everyone is there, but the decision can take place through such a forum.

Ms Willmington: If this is one way of necessitating case conferences happening, it is another inadvertent benefit of the Bill. The alternative is that people just have these decisions made for them. They have no opportunity to challenge them or discuss them. It is very much in closed situations rather than in these multidisciplinary ways, where you get other people prepared to speak or challenge them. That is a very positive thing.

Q118 Lord Pearson of Rannoch: When you envisage these conferences with professionals and so on, they are speaking on behalf of the intellectually disabled and people with severe learning disabilities and not so much on behalf of the mental illness group or elderly people who become mentally incapacitated. Where do you see the wishes of the family in all this, particularly the family carers who may have been looking after some of these people for a very long time and who just may know them better than the whole case conference put together? Where do you see the influence?

Ms Willmington: It is central. That is one of our reasons for having a case conference, so that it can involve anybody who has something to contribute and so that decisions are made which do include those sorts of discussions.

Mr Foster: This goes back to the earlier question about where is the focus and the best interest and indeed is it on the individual.

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Q119 Lord Rix: Surely parents and carers are generally included in all case conferences?

Ms Willmington: Clive is nodding his head here!

Mr Evers: Shaking it!

Q120 Lord Rix: Speaking personally, it certainly happens in my case, but it obviously does not happen in yours.

Ms Willmington: There should always be the opportunity for the individual concerned to state who they want, so obviously there may be times when they should not be and actually it is appropriate for them not to be involved. I think our concern, particularly with older people, is that reviews tend to be very much paper exercises that happen often in offices and do not really tend to consult people in a way that we would want. Now, somebody who has got full capacity and is articulate can challenge it, but somebody without capacity in that sort of situation does not have the recourse to challenge it.

Q121 Baroness Barker: Turning to lasting powers of attorney, in your submission the use of the word “parameters” rather suggests to me that you are not happy about the way in which this particular section has been drafted. I have noted in your submission that you have talked about issues such as checks and balances and tests of the immediate risk that we were talking about a moment ago. I suppose the issue that I want to focus on is the one that you have led us to which is really about the way in which lasting powers of attorney would be triggered, when and how. Clearly you do think that, as drafted, the lasting powers of attorney are too wide, so I suppose the logical question is how would you see them more closely defined?

Mr Evers: I am not sure if we necessarily think that the scope of the LPA, as drafted, is too wide. It is certainly appropriate in the sense that it covers a donor’s personal welfare, property and specified matters. People will want to be able to choose the powers they require and this really also enables the donor to appoint more than one person to act for them both individually, jointly or jointly and severally, so I think that there are some controls in that sense. We would certainly like clarification on the parameters of LPAs and, for example, clarification in relation to clauses 16 and 17 in the Bill on personal welfare, property and affairs, so some further discussion and clarification in relation to that list would be helpful.

Q122 Baroness Barker: Bearing that in mind, do you think that the exclusions as to who could be appointed an attorney are sufficient or not?

Ms Willmington: We basically would like to see some additions to that. One is that we feel there should be a duty on the court of protection to investigate if there are any potential conflicts of interest. An example that springs into my head is an example of a care home owner who takes out LPAs on all of their residents. At some point there has got to be something that triggers some concern about

that because of the concern about undue influence, so we think that the court of protection should have that duty. We would also like there to be some sort of duty about them determining the appropriateness of the person in terms of checking against criminal record checks and also about the local authority, in the process of establishing the covert protection for vulnerable adults list, listing people who would be inappropriate then to act as LPAs, so obviously we would like to see that included as well.

Q123 Baroness Barker: Moving on from that, do you think it is right for a non-medically qualified attorney to override a professional clinical judgment or would you think that such decisions being made would be within the confines of what you have described as a case conference?

Mr Goss: I could comment on that one, if I may. I think the main point to keep in mind is that clinical judgment has its limitations. It is only a judgment and may not even lead to the desired clinical outcome, so bearing in mind that clinicians are rarely in a position to know the values or priorities and life experience of a particular patient, we think that the lasting power of attorney, if given that authority, should be allowed to override clinical judgment.

Mr Foster: The issue is the difference that we would see between the LPA and the general authority. The LPA is the person who is specifically chosen, an individual to represent their views and their interests and, therefore, we would be in favour of that person being authorised to make the sort of judgments that the individual would themselves make if they had the capacity to do so in that situation. Whereas the doctor might say, “This treatment is plainly in your best interests”, I, as an individual, can say, “Well, thanks, I hear that, but I don’t want it”, and we think that is a reasonable distinction to make for the attorney as well.

Q124 Baroness Barker: I suppose a concern I want to follow up is that given that an LPA would have both financial and welfare elements to it as opposed to the old restriction, that opens up the potential for different people, for example, your example of care home owners, to have an interest in this that they would not have done under the old system. I wonder whether based on the old system of enduring powers of attorney you think that there needs to be a higher level of qualification for those acting as attorneys or not.

Mr Evers: Possibly introducing a higher level of qualification would be helpful, but one of the other proposals in the Bill which would act as a check is the requirement to notify an additional third person beyond the donor and the donee, so that should provide some extra safeguards as well.

Mr Goss: I think this is a good point. We would be very inclined to advise donors that it would be essential to think very carefully if they want a lasting power of attorney to have both a financial and a welfare voice on their behalf or appointing two people for the separate roles. I think this is probably

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wise for many people and of course you can get the situation where there will be an overlap. For example, if it comes up that you have to sell your house to finance care home costs, then it would need to be a joint decision if you have appointed two LPAs.

Q125 Mr Burstow: I just wanted to pick up issues around conflicts of interest, particularly where there were both financial and welfare responsibilities being given, and I take the point which has just been made in response to the last question. The scenario I had in mind was one where the local authority is given either responsibilities as an appointed deputy or a hospital is the LPA. The local authority as a whole has a fiduciary duty to its local taxpayers to get the best for its revenues and it also has the legal right to have regard for its resources when it makes decisions about care services. How could a conflict arise between those duties and the duty that this Bill would confer upon a local authority if it took on a deputy or an LPA responsibility?

Ms Thompson: I suspect that a local authority would only take on a deputy role because currently local authorities do not become enduring powers of attorney. I think there is a real issue here and there always has been an issue in relation to local authorities acting as receiver when they are both the collector of finances as well as making sure that the person does have their money and this has been a longstanding problem. I think it is an issue that really does need to be looked at very carefully when we are dealing with both welfare and financial decisions when they do have such a vested interest in both and I think it is something that the Bill does need to address both in relation to local authorities and also in relation to those people who are perhaps going to be the attorney, have been chosen by the individual, but obviously are those people who are likely to benefit from the estate and there do need to be regular checks on how that is working and that is very much a court of protection/public guardian office role.

Ms Willmington: I think our position is that we want more emphasis on reviewing and checks and balances and safeguards rather than *carte blanche* excluding groups of people because I think what we do want is people to be able to choose who they want as their LPA. Obviously in some groups they will actually want someone who works in the local authority, so we did not want just to say that no, we do not want these people, but it is about making sure that if there are these people with interests, there are sufficient reviews and checks and balances and safeguards so that that would be monitored and hopefully protected from.

Mr Evers: We also understand that there are random checks on LPAs taking place in Scotland as the legislation has been introduced and that is something that could also be considered here.

Ms Thompson: And also the requirement on an LPA to keep financial records as well so that those are there so that if there was a random check, there would have to be records to show how the money

had been spent. I think there is another issue in relation to LPAs that although currently the list for EPAs is a long, long list of people they would have to contact, we do have some concerns about the Bill as it is currently written and we feel that there should be one other party notified on application because it could be so easy for there to be undue influence on the person who might be having an eye to the finances and is wanting to take over as an attorney and if there is nobody else contacted, then that could all go through and I certainly think that the public guardianship office does need to look very closely at those where there is no other person named. It is a question of how one actually does that and whether you could actually get a situation where the donor does have someone named that is checked without necessarily the donee knowing who that person is.

Q126 Laura Moffatt: I just want to press you a little bit more on the concept of splitting the responsibilities of welfare and financial matters. I want to ask you to expand a little more on what you were talking about, having a proper appeal against an LPA by somebody who may have a temporary lack of capacity and then returns to capacity. Do you see a scenario, if you had a divided responsibility, where someone who is the subject of an LPA would say, "I think you made the right financial decisions for me, but I think you made the wrong welfare decisions"? It seems to me that there could definitely be some difficulty there. Perhaps I could just ask you to expand a bit on how you believe an appeal would work in that situation.

Mr Evers: I think it is a very searching question and there is a lot more to be done on that. I do not think at the moment there are necessarily sufficient mechanisms in the Bill for relatives of somebody who subsequently becomes incapable to appeal. There are questions about whether they would have to go to court to revoke the LPA and, if so, what would the costs be of that. Again there are timing and support issues and I think that again is another argument for the need for advocacy support on it and issues like legal aid would also help. Arbitration is one possible solution to that, but I think there are a lot of questions which still need discussion around that.

Ms Thompson: Also the very fact that you have fees for registration is going to raise issues. The idea is that an LPA would be registered normally before the person lacks capacity, so there are two issues about that. First of all, with the fees as they currently are, people might not be too keen on registering something which they might never need to use because they might never lack capacity, and they think they will leave it and they can register it if ever they do need it, so you are back to the old EPA issue about who decides when you lose capacity enough to get it registered. The second point is another financial issue of if it is registered, the banks on the whole will not be seeing the individual, whether or not they are dealing with the finances of somebody who has just given express permission for somebody to go out and get £1,000 out of their bank account

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and is perfectly capable of doing that or somebody who lacks capacity completely, whereas at the moment with the way that EPAs work now, the bank is aware when someone clearly lacks capacity, so I think there is a big issue around how the banks would deal with that.

Mr Foster: To come back to the question you were asking about, challenging one decision rather than another, it seems to me that there are three areas of challenge. One is to say, "I actually have capacity to make my own decisions", and that is, I think, ultimately a matter for the court and in fact clause 22 of the draft Bill does talk about powers of the court in relation to the lasting power. The second would be the fitness of the person if you thought the individual was making a succession of decisions that you thought would instantly disqualify them. That is a more difficult issue and it would be hard to challenge on one small point. It may be necessary to lump them together and say, "This makes the person palpably unfit". At the moment the Bill has no mechanism for dealing with that. The third would be that if there was a major decision to be made, and this is what we talked about earlier on, what are the boundaries, if you like, and what should be referred to the court for a decision, like major invasive surgery as an obvious example and selling a house would be another.

Q127 Lord Pearson of Rannoch: I wonder if you think there are sufficient checks and balances on the face of the Bill in relation to the powers of court-appointed deputies and, secondly, will the court of protection be sufficiently accessible to those with mental incapacity?

Ms Willmington: It is very similar to what we said about the LPAs, that there should be a duty on the deputies to investigate conflicts of interest. We feel that also that needs to include the CRB checks and protection for vulnerable adults list. We also were concerned about the need or we felt there was a need for an independent assessment of capacity and one of the things that we did feel that was different from the LPAs was that actually deputies should not be able to make advance statements about the withdrawal of medical treatment, decisions to withdraw or withhold medical treatment. Whereas we felt we were happy with LPAs because they were nominated persons, with the deputies, because they were appointed by the court, we felt it would not be appropriate for them to make that decision.

Ms Thompson: There is always a problem with the very word "court" in that people think courts are for particular issues. So the court of protection so far is not a court that is well known, so there are some real issues about making sure that people are aware that there is this court there, it is for them, it is accessible, and they are looking at it being locally accessible, and that should very much be made sure that people can actually access it and that again links back to the legal aid question because at the moment issues which go to the court of protection are not amenable to legal aid on the whole. So there is a real need for an advertising campaign about the court of

protection and how it works and making it as user-friendly as possible and informal as possible as well because I think there are issues about people actually thinking that courts are frightening places. On how the court is monitored, I would certainly suggest that there should be something like a forum of people set up where the court does actually report on a regular basis as to how it is being used and report also to Parliament and that there is feedback from these organisations to make sure that there is proper use of the court and people are actually able to access it. That would be very much done using voluntary organisations as well keeping an eye on this.

Ms Willmington: One of our concerns is that some of our suggestions mean that we would expect the court of protection to be very responsive and the time involved is going to be crucial in terms of how effectively people are going to use it. For example, we are suggesting that certain decisions be removed from the general authority and that becomes a single order of the court. One thing that we did suggest was a possibility is that if those decisions are not contested, whether that could be done by correspondence rather than an actual court appearance, so I think we were saying that decisions about responsiveness and timeliness will be actually really crucial in how effective this is going to be.

Mr Foster: I don't think this is the Alliance's response, but I think the Bill itself necessarily requires a much greater development of the work of the court of protection. Speaking personally, I would be very happy to see some sort of local devolved jurisdiction for lesser decisions, sort of arbitration-type decisions, rather than necessarily troubling the High Court. I want to add one thing which is about advocacy and again we are coming back to the same issue. I think it is terribly important, and I have no doubt that members of the Committee are aware of this, the advocate's role is to help and support and it is not to provide formal legal representation. We would be very, very concerned if when the Bill went forward all the emphasis was put upon supporting advocacy and not on providing some sort of public funding for legal representation because they are two very distinct roles.

Q128 Lord Pearson of Rannoch: Speaking again on behalf of the severely intellectually disabled, supposing that the court has appointed a deputy over a family member who has been looking after his relative for a long time, but he is getting rather old himself and beginning possibly to face the next world, should there be a mechanism in the Bill for making sure that that system, whatever the way of life of that intellectually disabled relative might be, continues after the deputy dies or would it all have to go back to one of your case conferences?

Ms Willmington: I am not sure we have actually discussed that scenario, to be perfectly honest.

Q129 Lord Pearson of Rannoch: Forgive me, but it is a scenario that is becoming very relevant because a lot of the bulge, parents, if you like, now are

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beginning to die off and this is a real problem we are going to be facing in quite large numbers in the next ten or 20 years.

Ms Willmington: I think it is one of those opportunities where we see the role for advance statements because that is one way of people recording their wishes for as long as they need.

Q130 Lord Pearson of Rannoch: This would be the deputy recording because the intellectually impaired person cannot.

Ms Willmington: That is the difficulty, that there are always going to be people that this would not be appropriate for, but we would hope that at least some method would be made and hopefully with the aid of communication there should be at least some reference to preferences. One thing that we are really keen to say is that if people are actually unable to make decisions, it does not mean that they do not have a view and it is a difference between the two. It is still really important to record that view even if they are not able to make their own decisions and that is one of the crucial roles we found with the statements, so that could be the case in that situation, that the person might not be able to make decisions, but they can record a view and that view could be recorded and used in the future for ever.

Mr Foster: As a mechanical footnote on that, there is provision already in the draft Bill, clause 19, for the court, when appointing one deputy, to provide for a substitute deputy as and when necessary which might be a helpful thing for people to use.

Q131 Jim Dowd: Mr Foster, can I just bring you back briefly to a point you made a few moments ago. You drew the distinction between advocacy and legal representation. There will be occasions, I am sure, when advocates could provide legal representation, but do you think, for the sake of uniformity, that the two roles should be separated in all circumstances?

Mr Foster: I have quite a strong view about this, advocacy in the mental health area, and in fact we have a database, coming back to Lord Rix's point, where we have tracked 460 separate mental health advocacy organisations, so there is quite a lot of work out there. I think this is the answer, but then I will be corrected if not, that we see the advocacy role as being one of essentially facilitating communication to assist the person to put forward their views or to establish what their views are and then relay them. In other words, it is largely a communication and assistance role. It is not a role to give advice or to take forward actions, if you like, on behalf of the person which the person has not themselves authorised or is not inherent in what the person has previously said. I can well imagine a situation, again speaking personally, where the advocate was sufficiently armed with information to be able to put forward what their client, if you like, would like to happen, but the client is not in a position to put that forward themselves, but I do think that is somewhat different from a lawyer arguing to a legal brief with a duty to the court in

certain circumstances which might override the duties to the individual client. It is a slightly different role and I think the point I was making, and I think it is a very fair question, was that there may be a tendency for financial reasons to put the emphasis upon advocacy and downplay the necessity for publicly funded legal assistance and we think this would be a very sad thing and contrary to the civil rights of the individual.

Q132 Jim Dowd: So you did separate the two specifically?

Mr Foster: Yes, I think they are separate roles and an advocate could speak in a public forum such as a court or other tribunal on behalf of the client if they knew what the client's express wishes had been in an advance statement, for instance, or if they had had sufficient discussion to know what the client wanted to be said, but I think that is a very different matter from arguing points of law and I would say they are distinct roles.

Q133 Baroness McIntosh of Hudnall: The draft Bill does make provision for advance refusals, but it is silent on any other kind of advance statement. Do you think the Bill misses an important opportunity there to clarify the law in respect of other kinds of advance statement, or should that be left to be decided by the courts on a case-by-case basis? Can I add to that a separate, but importantly related question which is about registration. Whatever kind of advance decision the Bill eventually provides for, and at the moment it is only to do with the refusal of treatment, should those decisions be registered in writing? At the moment the Bill does not provide for that, but the question of whether or not it would be possible to establish the existence of an advance refusal without registration and written evidence seems to be a fairly obvious one.

Dr McCulloch: I think the advance statements are very important as far as people's freedom and dignity are concerned when they have the opportunity to make a statement, when they have capacity and when they fear that they are going to lack capacity at some point in the future. We come across numerous cases where people recover capacity and things were done to them that they wished had not been done. A very simple example I came across recently was of a client who was involved with a service who was a strict vegetarian and who was fed meat during a period of incapacity and then was disgusted to find out that that had been the case because she had deep beliefs against it. If she had been given the opportunity to make a statement to that effect, she would clearly have done so, so I think it can refer to a number of issues where someone might wish to be proactive about stating something. Clearly in an example like that it should be possible for a service to provide a vegetarian diet. We are not talking about a massive expenditure of resources in order to enable that person's wishes to be met and it is very important for that person, so we would very strongly advocate that some kind of advance statement be possible.

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Q134 Baroness McIntosh of Hudnall: Just to be clear, you mean that you believe that there should be something on the face of the Bill to that effect?

Dr McCulloch: On the face of the Bill, yes, because I think at present clearly there is a common law ability to make an advance statement, but our experience as an organisation, and we have been undertaking research on this, is that there is not a very high degree of uptake by service users because they are sceptical because it is not enshrined in legislation and also that clinicians and care staff commonly disregard those statements also because they do not consider that they would have the weight or authority, so we think that there is enormous benefit from putting this on the face of the Bill. I think it would be a general view, but probably not an exclusive one, that that statement should usually be written down and placed in an appropriate place. Clearly some people may have capacity, but may not be able to write their own statement, in which case there needs to be a mechanism for the recording of that wish by another person.

Mr Goss: I think you asked the question whether it is a missed opportunity not to have mentioned advance statements. The short answer is yes. We do think that those who wish to opt for all reasonable measures to be taken to prolong life must have an equal opportunity to make their views clear. This would not of course oblige doctors to use treatments they considered inappropriate, but would forestall misjudgments about quality of life issues. We believe that a request for treatment is just as important and relevant as a refusal in judging how best to care for an incommunicado patient. We want the Bill to embrace the needs of everyone, including those who want to be kept alive to the extent that its impact upon them is reasonable. We also believe that advance requests for treatment are a vital aid for the disabled in securing good care. Sadly, in our experience, from our helpline, e-mails and letters, some clinicians do deem the quality of life of the disabled less worthy of supporting. In terms of referral to the courts, statements are no different from a refusal in that disputes between interested parties at the end of the day have to be resolved in the courts. Now, as far as finding out the existence of either an advance statement or, more importantly perhaps, an advance refusal, we would confirm what my good friend has just said, that there ought to be a mechanism at least to lodge an advance refusal, particularly if it is made in writing, tape or audio form, and that there must certainly be an obligation on healthcare providers to check whether such a refusal exists. Refusal should not be invalid if not registered or lodged, but the education campaign should make clear the benefits of registering a written document. If the Bill is to achieve its purpose, it needs to minimise the scope for using administrative problems as an excuse to override a patient's instructions. Sadly, that does happen. An oral refusal should still be valid, provided it can be demonstrated that it is sustained and has been properly witnessed in the sense of having been heard, noted and logged. As to the question of how do you

find out if you do not have a system for registering, which I think you asked about as well, the short answer is: with difficulty. We recommend a legal obligation on clinicians to check with a central registry or a place where they can be lodged, and this is in addition to checking with the individual's GP and nearest and dearest. Unfortunately some people have neither. As a last point, a central register would at least offer additional protection against failures to identify the patient's wishes or instructions.

Ms Willmington: I would just add that making decisions has not actually gone as far as saying that we require a central registry. Our position was more that it needs to be logged and it needs to be logged with everybody involved in that person's care and we felt that the paperwork involved in a refusal should have a box which is ticked if there is an advance statement, so that should be part of the mechanism that it happens. We felt it was important as part of the law because we could then extend the clause which actually makes it a criminal offence to destroy or conceal an advance statement and that would give it much greater legal status and respect. We see it as a great opportunity for actually facilitating communication and discussion, that a lot of conflict results from situations which have not been discussed in advance or people have not communicated their wishes or views, so it is a great mechanism hopefully for preventing further conflict.

Q135 Chairman: I do not know if you saw the interesting article in *The Guardian* a few weeks ago by Jane Campbell, whom you might know. As you know, she is very, very severely disabled and she went into hospital with pneumonia and she was really very seriously ill. The doctor said, "I presume that you will not want to be resuscitated", obviously referring to her condition and disability. If she had made an advance statement that she wished to have resuscitation, under the common law that would apply now, would it not?

Ms Willmington: I think so, but I think our concern is that it would apply, but because it does not have the legal status and legal recognition, people would not actually feel obliged to act upon it.

Mr Foster: At the moment in common law that is the case, yes, and the question is to what extent you regularise it and put it into statutory form. Then there is the second question which is the process to be gone through to approve that, but yes, you are absolutely right.

Q136 Chairman: Presumably if in fact it was in the Bill and within the framework of law, then the doctors would not ask the question? They would not even assume that you would not wish to be resuscitated because the advance statement would have been made and protected in law.

Ms Willmington: Absolutely, because they would be able to refer to this advance statement and the situation would never occur.

Ms Thompson: I did actually see a film of Jane recently discussing that very point and it was incredibly powerful because she is a strong-minded

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lady and was too frightened to go to sleep because she was so worried about what they might do. I think if that could have reassured her, having it on the face of the Bill, knowing that she had got an advance statement would have made a big difference to her illness.

Q137 Mrs Humble: Can I follow up the point about registering advance statements and where you would register them and the problems that there might be with regard to data-sharing and the civil liberties issues. There have been developments over recent years as there is more and more data-sharing between organisations, but there are quite clear civil liberties issues there. You mentioned, Kathryn, the fact that all the people involved in the care of that individual should know whether or not they have made an advance statement, but I will put to you the situation, representing, as I do, Blackpool where lots of people come for their holidays. There might be an individual coming, accompanied not by their regular carer, but by somebody else who may not know about any advance statement. If they are taken ill, they could go into an unfamiliar hospital and the only way that a surgeon there would know about an advance statement would be if there was a central registry and the whole issue then is accessing that information, so as to how detailed the information would be on that registry, should it be that Mr, Mrs or Miss X has registered an advance statement or should it include details of it? Would that surgeon instead be choosing to act under a general authority of what they believed was in the best interests of the individual even if his or her judgment on that best interest might actually be at variance with whatever is in the advance statement? It could be quite complex. Do you think that there should be some sort of central registry and, if so, how much information should be on it and what restrictions should there be about access to it?

Ms Willmington: My understanding of our position as it stands is that we were talking about logging it and, therefore, logging it with the local care team. Really our concern was about data protection and how you would share that sort of information, but what we would be hoping is that people would then not only share that, but have that with them. Obviously there are always going to be situations then where they would be concerned about, "How will they know?" and I guess there is no definite resolution to that, but I think it is a double-edged sword. Do you go for a central registry and then have all the concerns about data protection? I do not know if people want to add to that.

Mr Goss: I think this probably falls into the category of that famous phrase, "One of life's insoluble problems".

Q138 Mrs Humble: But we are here to solve the problems and make recommendations.

Mr Goss: I will rephrase it to "soluble opportunities". I will be advised by my many friends on this, but if it is right to lodge an LPA and you do not run into problems of confidentiality in finding

out if a person has got one, I am a little bit pressed to see why you would run into problems with an advance statement. Just as a matter of interest, at the moment, because there is not this facility, though there is in many states in the United States, who have a central registry for advance refusals, there are people who lodge them with an organisation called Medic Alert. Now, Medic Alert, you will be familiar with, is this organisation that helps people who may fall over in their home and it warns the authorities. Well, they have provided a facility now where you can in fact lodge your advance refusal with them and they will supply you with a bracelet if you want that points out that you have an advance refusal or statement and how to get in touch and check it out.

Q139 Chairman: I suppose if we ever did get to the point where we had the famous smart card with all of our medical history on, that would be the obvious place to put an advance refusal or an advance statement.

Mr Goss: Yes, absolutely.

Mr Foster: There are two possible ways through this. We have done a lot of work around confidentiality and data protection is a real issue, but with the move towards electronically held records, I think this is possibly a transitional point where in five years' time, I would imagine, a surgeon in Blackpool wishing to operate on somebody they do not know would call up the medical records and if there is an alert, saying, "Advance Directive—click here" or whatever it may be, that would allow it. There is just one point, if I may, on the question of registration. Ultimately there is going to be a question of evidence. Is this advance statement, advance refusal available and can people find out if it is? The fact that it is involved in a central registry or appears in someone's medical records will be helpful from that point of view, but ultimately if a person turns up, they have been knocked over and in their pocket is found a statement, saying, "In the event of my not having capacity, I absolutely refuse X, Y and Z", or, "Please give me whatever helps me", that must be given the same validity as something that is officially lodged, I would suggest.

Q140 Baroness Knight of Collingtree: Could I say a couple of words on that last point because I know of one organisation already which provides people with a card which they carry, like a donor card, which seems a lot less complicated than having registers and all the rest of it, which says, "In the event of my becoming unconscious and being in hospital, I want to be kept alive". Now, that has got just as much status as a donor card and I think that is important not to forget.

Mr Goss: Absolutely.

Q141 Baroness Knight of Collingtree: The questions I really want to ask have been prefaced in the explanatory text prior to questions, "Following the House of Lords judgment in the *Bland* case, medical treatment includes the provision of artificial nutrition and hydration." Now, I want to make it

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absolutely clear for the record that that was the BMA's decision and it is not legal at this time, but the draft Bill, if enacted, would give the *Bland* decision apparently a statutory basis, and this is a point which is worrying a very great many number of people, and it is also the point at which my question falls into two parts. One is not only the provision of artificial nutrition and hydration through a tube down the nose or a peg in the stomach, but also even when patients are able to take food and liquids through the normal way, that also, since the *Bland* judgment, has been decided is medical treatment. In other words, when we all go for a meal, we are actually having medical treatment, which I am very concerned about, I may tell you. Is it your view that that definition of medical treatment should (a) include the provision of artificial nutrition and hydration and (b) the normal intake of food?

Mr Evers: This question is a very emotive question.

Q142 Baroness Knight of Collingtree: It is a very important one.

Mr Evers: It is very easily misinterpreted. The Alzheimer's Society and our counsel believe that it is very inappropriate for a person with advanced dementia to be given artificial hydration and nutrition solely for the purposes of prolonging life. The purpose should undoubtedly be about maximising the quality of life to the individual at that stage and the BMA, as you have said, have given guidelines on withholding and withdrawing treatment. We have serious, ongoing concerns about the frequency with which people in the terminal stages of dementia continue to be artificially fed and hydrated. It is important that we know that there are alternatives to that because when somebody can no longer eat or take fluids, then there are ways of one-to-one nursing, providing water, sips of water for the individual, sitting by the person and giving them basic comfort. These are real practical alternatives to the invasive approaches of tube feeding, so these are issues that we think need to be taken into account and there are options within the Bill to do that.

Q143 Baroness Knight of Collingtree: Before you finish, Mr Evers, you said "the quality of life". Now, that is one of the big problems, is it not, because who is to decide on a person's quality of life? If a person is paralysed, one doctor may say, "Your quality of life is so bad, you may just as well die", whereas the person who actually is paralysed may not think along those lines. Is that not a difficulty in saying that you decide by the quality of life?

Mr Evers: It is a difficulty, but we can also define quality of life. There is a lot of discussion and research into how quality of life is decided and, in addition, the opportunity for advance directives and statements whereby an individual can make provision for what they wish during those circumstances. Thirdly, where there is a close relative, that relative or partner will undoubtedly know how that individual would have wanted to be treated in those circumstances.

Q144 Baroness Knight of Collingtree: I am so sorry, but you are not answering the question I have put. The question I have put is: would you think it right to call feeding people or giving them water medically treating them? I did put it into two separate categories, one, if it is the peg or the tube and, two, if it is the normal way of eating. I just want to know whether you think that should be described as medical treatment or not.

Mr Evers: Medical treatment would include basic care. That is our understanding and basic care would include, as I have described, giving sips of water, giving comfort and that is what we believe should be included and the individual should have the option to have that made available to them.

Mr Goss: It is difficult to know where to step in on this one, but I will just offer a few thoughts that I think may bear on the subject. There is a great danger of allowing the issue of artificial feeding and hydration to get blown out of all proportion and hijack the Bill. Very few people, in our experience from our helpline, letters and e-mails, actually opt for this form of refusal. In any case, if I have read the Bill correctly, attorneys will only be able to make this choice if specifically given the power to do so under clause 10, provided of course that the BMA's plea for its removal is not accepted. I stand to be corrected by Baroness Knight because I am not a lawyer, but we thought that, though we are probably misinformed, artificial feeding and hydration is treatment and it is certainly invasive treatment. It has always been recognised that we have the right to refuse treatment for any reason, for no reason or an apparently irrational reason, regardless of consequences. Now, it has been suggested that withholding artificial treatment, feeding, is euthanasia by neglect, as I think I saw the phrase in the questions. Well, we would only comment that withholding such treatment at the express request of the person involved can no more be classed as euthanasia by neglect than not amputating both legs of a patient with circulatory disease in order to preserve life.

Q145 Baroness Knight of Collingtree: That I fully understand, if anyone does not wish to be fed in that way, but I am still wanting an answer to the question because it is also the case that withholding food and liquid when anyone can take it normally is classified as medical treatment. Do you think that is correct or not?

Mr Goss: I can only speak directly for Patient Concern. We think that what one might term "normal feeding" is not medical treatment, but artificial feeding is medical treatment on the grounds that it is invasive and we have in fact in our organisation, sadly, either individuals themselves or more usually their nearest and dearest who have said that the individual has told us that if they had known what was involved with invasive, artificial treatment, they would have declined it.

Ms Willmington: My understanding of basic care is that it is about making sure that that person is comfortable and that everybody should always have

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access to basic care, so they should always be made comfortable and they should always have what we are talking about in terms of moistening of the lips and sips of water if that is appropriate, so our definition of basic care is anything that I would in my non-medical way term as good, palliative care really and that is about quality of care.

Mr Goss: Can I just add one further thought on the concept of basic care. It may be for consideration that this ought to be defined in the Bill and if that were the case, we would suggest that it has three elements. It consists of feeding those people who are able to accept food and liquids in the normal manner rather than by invasive treatment, it would include basic hygiene because, after all, that is in the individual's best interests, for the benefit of staff and other patients, and, lastly, pain relief. There is a difference of opinion on the question of pain relief. Some people take the view that it is an integral part of palliative care and, therefore, should not be optional. On the other hand, we find people who take the view that they would rather remain conscious as far as possible and, therefore, do not necessarily want full pain care. Lastly, one has to remark that there are some people who believe in the redemptive power of suffering.

Q146 Baroness Knight of Collingtree: I do not think we are so much concerned about that. There are two other points and both of them, oddly enough, touch on something which has been said previously this afternoon. First of all, do you think that the provision of basic care, and I am grateful for Ms Willmington's description of that, such as food and liquid, should that be excluded from the scope of an advance refusal or even perhaps the powers of attorney to refuse treatment?

Mr Goss: It looks like I have been put on the spot again! We would take the view at Patient Concern that basic care should cover normal feeding, ie, without any technical things involved and you should not be allowed to refuse that *per se*, but when it comes to invasive treatment, well, you should have the right on that the same as anything else.

Ms Willmington: My understanding is that we made a clear distinction between medical treatment and basic care and that medical treatment is something that you can refuse, but everybody should have access to basic care.

Q147 Mr Burstow: I just wanted to pick up on a thread from a previous question, if I may, which was the point that Mr Goss was making about an anxiety that he and possibly others might have that this question of artificial feeding and hydration and so on could somehow hijack the Bill. One of the things that I understand the Making Decisions Alliance was established to do was to enter into dialogue with other organisations that might have such concerns. I would be very interested to hear how successful that dialogue has been and how many other organisations have responded to that.

Mr Goss: I have been invited to a meeting of these groups tomorrow and I will make a point of attending to hear their views.

Ms Willmington: I think the other point is that the joint chairs of the Making Decisions Alliance will actually be present at tomorrow's session, so they are probably in a slightly better position to answer that one.

Q148 Baroness Knight of Collingtree: So we watch this space! Finally, could I ask you this: in what circumstances might starving a patient to death through the withdrawal of artificial nutrition and hydration be in that person's best interests?

Mr Goss: The answer is, I think, that it is only in the best interests of a patient who has clearly and specifically opted for this rather than enduring a long, drawn out, living death. In effect, it is the least worst option or, alternatively, if the patient has given the choice to their clinician because they do not want to make it themselves, that is what the clinician decides is in the best interests of the patient.

Mr Foster: I cannot speak from the Mind perspective, it is in an entirely personal capacity, but my father was in intensive care and was artificially ventilated for some weeks and was artificially fed. There was a point when he was rallying but there was a point at which his systems began breaking down completely, at which point I do not think the family, who loved him very much, wanted him to return. There was a point at which we felt, "This cannot be right. We are artificially prolonging his life when there is no prospect of his recovery". I think that is a relevant factor. That was the situation but it was very difficult because it was put by the medics on that occasion, we were asked for our views but we could not possibly give a view whether it was in his best interests or not. The doctor very helpfully said, "I should really make the decision, I just wanted to know what you thought based on your knowledge of him. You are quite right, he would not have wanted to be kept alive like that." I do not know if that helps.

Chairman: Thank you. There is an important point on the Human Rights Act.

Q149 Jim Dowd: Yes, the Human Rights Act, Article 2, Schedule 1. Committee members have received various views on this. To some degree with most lawyers you pay your money and take your choice, but it depends who you pay, and never ask the question until you know the answer. The Joint Committee has said this is compatible, we have had other submissions it is not. What is your view on the compatibility of the provisions in the Bill?

Mr Goss: My understanding, and I am not a lawyer and I say that again, is that the Human Rights Act is concerned with right to life which is not about specifying an individual obligation to life. The obligation to life is essentially assumed by some religious faiths which we are all at liberty to accept or reject. We feel in the end the law should not allow a minority set of such views to prevail over the

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majority and be enforced on them. I am sorry if that is provocative but we are, as my good friend said, into emotional territory here.

Mr Foster: May I approach this from a slightly different angle, again a lawyer's angle. I am pleased to say all advice of mine is free of charge.

Q150 Jim Dowd: In which case it may be worth what we pay for it!

Mr Foster: We discussed this before coming before this Committee. I think the problem is arising because Article 2 of the European Convention, which is as you say in Schedule 1 of the Act, talks about right to life, there is nothing to say you have an obligation to keep yourself alive whether you like it or not. The problem comes because in the Human Rights Act itself there is a duty placed upon public authorities to uphold and enforce the Convention rights. I can only speak again from a personal point of view, I would say there is no incompatibility between the draft Bill and the European Convention, the reason being that the duty upon a public authority is to uphold a person's right to life. If an individual said, "I actually do not wish to be kept alive in these circumstances"—and Mind hears from a lot of people who say, "I cannot tolerate this any more, I have been through this, they have pulled me back and back and frankly I am fed up with it"—at that point I think the individual is saying, "I do not wish to uphold my right to life". Then, of course, there is an issue about how much reliance we put upon that and what their state of mind was when they said those things, which of course must be looked at. But ultimately I would say that has let the public authority off the hook from their duty to keep the person alive when they have made it clear they do not wish to be. That is the best I can do.

Jim Dowd: I am very grateful for that. I am fairly certain we have not heard the last of that.

Chairman: We did have a question about education, Question 18. If you would like to write to us on that, that would be helpful. We have touched on the question of advocacy but if there is anything else you would like to say about it, that would be helpful too.

Baroness Barker: Can I ask, when you answer that question, there is just one particular question I would like you to address, and it is whether the advocacy services established for the purposes of this Bill need to be separate from other advocacy services. A number of us around this table have dealt with a variety of different Bills in which the issue of advocacy has come up. It is really whether it is possible to have a multiple advocacy service. If you could address that, that would be helpful.

Mrs Humble: I was going to raise that and ask you a series of questions on advocacy as President of Blackpool Advocacy. Much of the funding for advocacy services now is short-term funding to develop specific services. Where is the money going to come from? Should there be national funding for a national service? Should it be national funding given to the local councils to develop local services responsive to their needs? Should it be ring-fenced funding and therefore on-going funding? Then of course there is the issue about the quality of the service, monitoring it and also letting people know about the service and what it means. This is picking up in a way on Jim Dowd's point, because simply using the word "advocate", a lot of people think "lawyer", and it is not a lawyer, so a lot of people do not understand what advocacy services do. How best could people out there who could benefit from the services know they are out there. If you could address those issues, that would be helpful.

Chairman: Another extremely important question is Question 21. We would like your views in writing on what you think the effects would be if your proposals are not implemented.

Mr Burstow: Allied to that, it would be useful if you could give us as part of the response to Question 21 some indication as to what the minimum requirement would be, ie what your sense of priorities would be amongst the things you have put forward to us for any additional resources which might be available.

Chairman: Thank you very much indeed. It has been very helpful, a most stimulating session, and we have some more to come, as you know.

Wednesday 17 September 2003

Members present:

Barker, B.
Carter, L. (Chairman)
Fookes, B.
Knight of Collingtree, B.
McIntosh of Hudnall, B.
Pearson of Rannoch, L.
Rix, L.

Mr John Bercow
Mr Paul Burstow
Jim Dowd
Stephen Hesford
Laura Moffatt

Witnesses: **Mr Steve Broach**, National Autistic Society, **Ms Caroline Clipson**, SCOPE, **Mr Richard Kramer**, Turning Point, **Ms Hazel Morgan**, Foundation for People with Learning Disabilities, and **Ms Susannah Seyman**, Down's Syndrome Association, Making Decisions Alliance, examined.

Q151 Chairman: Can I start by saying good afternoon, thanking you for the written evidence and taking time to attend. We are required to report on the draft Bill, we are not preparing a White Paper on mental incapacity, therefore, all the questions you have seen are structured around the structure of the Bill and that is our task, to report on the draft Bill. Perhaps you could all introduce yourselves.

Mr Broach: Thank you very much and particularly for this second day of evidence of the Making Decisions Alliance before the Committee. Our colleagues yesterday did not take the opportunity to introduce the Alliance. There are 27 organisations representing millions of people with impaired capacity and those who care for them. I am Steve Broach, I am co-Chair of the Alliance and here also to represent the National Autistic Society. The only point I would like to make regarding autism is that it is a spectrum disorder and that for the vast majority of people with the autistic spectrum, hundreds of thousands of adults in England and Wales, their capacity is not going to be easily ascertained. It is not black and white that they are able to make decisions or unable, so our key concern is that an accurate and informed assessment has to take place before the powers in this Bill apply to those adults and also that they have the opportunity to challenge both assessments and decisions that are made about them.

Mr Kramer: I am Richard Kramer and I am head of policy at Turning Point. The opening comment I would like to make is really to talk a little about the history of learning disability because in the past it was assumed that people were not competent to make any decisions of any sort, so decisions were often made by staff in service settings without any attempt to distinguish between decisions that they could make and those that they could not or could make with support and the emphasis unfortunately was on group rather than supporting individual decision-making. Sometimes the intentions were benevolently misguided and sometimes it amounted to exploitation or inappropriate treatment and more routinely people who did not need hospital treatment spent a lifetime in hospital for the convenience of people, and our society is benevolent and that is why this Bill is so important because we feel that the absence of legal procedures in decision-making actually discriminates against people who cannot make decisions and the need to see this legislation in the broad light of disability discrimination legislation.

Ms Clipson: My name is Caroline Clipson and I am from the disability charity SCOPE, which has a focus on people with cerebral palsy. Cerebral palsy is a condition which can affect people in very many different ways, but my particular interest and involvement in terms of the Making Decisions Alliance has been to look at those people who, with different conditions, have their communication impaired in different ways and so that is perhaps what my particular interest has been in, and some of the issues I will be talking about relate to that issue.

Ms Seyman: I am Susannah Seyman from the Down's Syndrome Association and the DSA has campaigned for many years about the inequalities in healthcare for people with Down's Syndrome and this Bill is of particular interest to us to protect people who suffer from bad decisions which have been made.

Ms Morgan: I am Hazel Morgan, head of the Foundation for People with Learning Disabilities which is part of the Mental Health Foundation. The Foundation for People with Learning Disabilities uses its research projects to promote the rights of people with learning disabilities and their families. One area of our work recently has been around choice for people with severe and profound learning disabilities which is obviously very important in the context of this Bill. To my work I bring the experience of having been a family carer and the mother of a son with severe learning disabilities and during his lifetime I became aware of the issues around decision-making, the issues for him and the issues for family carers, particularly in the final year of his life when he had many healthcare issues as a young adult.

Q152 Chairman: Thank you. In situations where "there is a risk that the individual's own best interests would not in fact be the paramount consideration", do you believe that referring to "best personal interests" will significantly impact on decisions taken on behalf of individuals with incapacity? Does the proposed "best interests" checklist strike a balance between supporting the autonomy of the person with incapacity and providing them with protection?

Mr Kramer: I think the starting point is that there is concern over the term "best interests" largely because it is an outdated term. It is used principally in courts of law now to determine the right of medical practitioners to make decisions about

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medical treatment, so the term is outdated and it does not reflect the wide decision-making powers that will be in the Mental Incapacity Bill. The second point is the point that has been raised by the Law Society, which we support, which is the terminology “best interests” and the concern that it may allow people to impose their views on what is in someone’s best interests or what they would choose for themselves. We think that because of that and because it may be difficult to change a person’s interpretation of “best interests”, a new term, such as “best personal interests” is needed. I think the most important point is the starting point for the legislation. The starting point is really to maximise people’s own decision-making ability and supporting that and that should be the guiding principle in the Bill. The fact that it seems that “best interests” is the guiding principle has given some misunderstanding that the Bill may restrict or impose a view over somebody’s ability to make decisions, so, as a starting point, the guiding principle should be the right to make decisions rather than making an alternative frame for those who cannot make decisions.

Mr Broach: The conversation yesterday and indeed with the Scottish witnesses focused very much on “best interests” and the difference between that and “benefit”. I think it is very important also to look at the early reports in the draft Bill, clause 2, and the safeguards it puts in around assessment in terms of how people should or should not fall under the powers of this Bill. Two very important ones are 2(2), that, “A person is not to be treated as unable to make a decision merely because he makes an unwise decision”. That is a very important safeguard relating to Richard’s point around assumptions about people with learning disabilities, and that is not in the Scottish Act. Also in 2(3), that all practicable steps have to be taken to help the person make a decision before they are described as unable to do so, again that is absolutely important, although it needs to be defined as to what practicable steps would be considered in those circumstances, a broad outline of the principal section of best interests and also the second clause in the Bill about the ability to make decisions.

Q153 Chairman: Would you be concerned if, under 2(2), a person clearly made a very, very unwise decision regarding their accommodation, their welfare or their finance or whatever? Even though it was a seriously unwise decision, you would stand by the right of that person who had made that decision?

Mr Broach: Yes, we would and the test of capacity that is set out in 2(1), that simply the person can understand the decision and also can understand the foreseeable consequences of it, if a person is fully aware of the consequences and still chooses to make that decision, that is their legal right.

Q154 Chairman: I suppose you would argue that they would be on the same footing as somebody with capacity who equally made unwise decisions?

Mr Broach: Precisely, that is right.

Q155 Baroness McIntosh of Hudnall: I just wanted to pick up on the issue you have already raised about Scotland and the terminology in the Scottish Bill. We asked your colleagues, as you have already noted, but it does seem to me that this “best interests” terminology is, as I described it yesterday, volatile and it does seem to me to be volatile, that it can have the potential to be used and abused. I am interested to know that given that you clearly accept that, you still feel that it is preferable to the kind of terminology that is in the Scottish Bill which describes quite clearly the necessity that there should be a benefit to the person on whose behalf decisions are taken. This is in the situation where decisions do have to be taken on somebody’s behalf where it is clear that they do lack capacity.

Mr Broach: As an initial answer to that, our thinking around this Bill was framed by the Bill that was put in front of us, so we have tried to amend the language that is used here and that is why “best personal interests” was one of our preferred options. In terms of whether “benefit” is actually preferable to “best interests”, I think the point to make is that both are subjective and a benefit to an individual is also not an objective criterion. It also means that it is impossible for someone to take a decision that is not transparently of benefit to that individual because even if the decision may be in the person’s wishes and feelings as the decision they wanted to take, you would not be able to take it unless it was to their benefit, so I think that both terms are problematic.

Mr Kramer: I think the Scottish legislation is good in that it has a statement of principle which defines the tone of the Act and ensures more consistent implementation and I think that is important. The Making Decisions Alliance have said that there need to be some principles that will set the tone of the Act and the main principle is the right to make decisions, the recognition of people’s autonomy, to preserve autonomy and to protect those with impaired autonomy. The other principles could be around a non-discrimination quality, supporting in terms of information, so there are a number of principles which can govern the Bill. The Scottish have chosen “benefit” which is a sound principle. There are other principles and I think that autonomy and the right to support decision-making would be ones for us.

Q156 Baroness McIntosh of Hudnall: I find it quite hard to understand what the real value is that is added by “personal” in relation to best interests. It does not seem to me to clarify it very helpfully and I would be very interested to know why you want to amend it in that way.

Mr Kramer: Because I think it can affect the way decisions are made. If you are thinking of the best personal interests, it can mean starting from the individual, thinking how the individual can communicate, how we can break down facts to a decision, how we can ensure the right support, how we can ensure the environment is suitable to allow

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decisions to be made in the calm environment, so looking at the nature of the decision, the timing of the decision and the use of communication methods, the word “personal” would promote good practice in all of those areas.

Q157 Lord Rix: How would you protect the best interests of the person with a learning disability who already has perhaps limited powers of decision-making, but then those powers are gradually diminished through age or mental illness? How would you see that the Bill should be written to protect such an occurrence?

Mr Kramer: I think the Bill does recognise that capacity can change, that people can develop incapacity with time and experience and, as you say, as people grow older they may develop dementia and lose capacity. I think that is recognised by the functional test and I think that is also recognised by the “best interests” test which allows people to participate in decision-making where they can do so, so someone who develops dementia may have a reduced capacity to make decisions, but they still may be able to participate in the decision-making process and should be encouraged to do so, so I do think the Bill is flexible enough and recognises that.

Q158 Lord Rix: Good.

Mr Broach: There is a second point there perhaps as well which was, as was mentioned by the witness from Enable, it should be possible for people with moderate learning disabilities to make powers of attorney and we must not forget that those powers could also apply to someone who has a disability and someone to represent him, but has capacity to endow that power to them, so in that situation of ageing and potentially coming on to dementia, they could make a power of attorney as any of us could.

Q159 Baroness Knight of Collingtree: Many years ago when I was a local councillor, I called on a lady whose condition worried me greatly. She was dirty, her house was filthy, her clothes had not been washed, I do not think she had had a bath in ages and, as far as I could see, she was not feeding herself properly. I finally, after a lot of effort, got her into a local hospital which she strongly objected to going to at all. I went to see her in it and there she was in a nice, clean bed, looking lovely and clean, but she died within a week. I have always been worried about what her best interests were in that case because I am horrified to say so, but I think her best interests were to be in her own filthy home and I still do not know, my Lord Chairman, whether I was right or wrong and I believe that I was wrong. What do you say?

Mr Broach: I think that is a very telling example, but I think there is a step before that perhaps which is that if this Bill becomes law, you would not have been able to take the lady into hospital unless you could demonstrate that she was not able to make that decision for herself. It is quite possible that although she was living in circumstances that were not ideal, she was able to choose to live in those

circumstances and, therefore, she would not fall under an inability to make decisions as set out in clause 2.

Q160 Baroness Knight of Collingtree: So the Bill would have protected her?

Mr Broach: I think the Bill would have protected her right to make that decision for herself.

Q161 Stephen Hesford: I apologise for missing yesterday’s session, so there is perhaps an absence of knowledge on my part, but I think I am picking up the drift. What I am worried about so far is that there seems to be an element of confusion in what is being said which I am not entirely happy is helpful to the Committee. You asked about the checklist, but I am not sure that has been addressed at all, the idea of whether the checklist is sufficient. The other is that there seems to be a confusion between assessing whether somebody has incapacity and then, if somebody has incapacity, what then you can do about it. The decision as to whether someone has incapacity or is incapacitated in some way to bring them within the Bill is a different stage from addressing best interests and so far it seems to be rolled up.

Mr Broach: Perhaps we should try to untangle it.

Q162 Stephen Hesford: Yes, for me at least.

Mr Kramer: I will deal with the first point because that is easy and it will give us time to think about the second. We do think that the best interests checklist is important. What is not clear in the Bill is the priority in terms of the checklist, what should be given priority in terms of that checklist, and the starting point is to support the person to make their decisions and make sure they have all the information to do so, so that is not in there. The other point that is not in there is the concern about supporting people who may have severe learning disabilities to make decisions who may be able to indicate their wishes through changes in behaviour and I think that is an important issue that is not included in the Bill, that someone may demonstrate pain and distress that they do not want to do something and that may be exhibited in changes in behaviour. If we are about supporting people with profound learning disabilities to make decisions, I think that is a very important factor that has to be taken into account. The third one is about the need to take into account issues around cultural values as well. If we are respecting people’s diversity, then I think we also need to respect their whole makeup and their cultural factors which may influence their decision-making.

Q163 Stephen Hesford: I still think that that has the confusion of putting the two things together. Are you saying that clauses 1 and 2 should be amended in some way in seeking to address the issue of if somebody suffers from incapacity?

Mr Broach: No. Our argument is that, as with the Scottish Act, there are principles, but essentially clauses 2 and 4 together form the principles of this

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Bill, but actually for us clause 3, presumption against the lack of capacity, is the fundamental principle, so the way it works for us is that we presume that a person has capacity, we then assess that capacity and we allow them to make their own decisions and we ensure that they are supported to make decisions and if they still cannot make decisions, then the checklist in clause 4 would apply.

Mr Kramer: But the prominence given to best interests has led to confusion about whether it is going to restrict people's right to make decisions and that is why the presumption has to come first and move clause 3 to the start of the Bill.

Q164 Chairman: Is the problem that this Bill entirely has a functional approach, whereas the Scottish Bill starts off with the principles and then you build the functional approach on to that? Is that your concern?

Mr Kramer: Yes, if you were to ask us what is the overriding principle the equivalent to the benefit for the individual, we would say the right to make decisions that they are capable of making and to be supported in doing so and that is lost in the Bill because if you look at it, someone could go to clause 4 and ignore clauses 2 and 3.

Q165 Baroness McIntosh of Hudnall: Would that lead you to suggest that the title of the Bill is wrong?

Mr Broach: Yes.

Q166 Baroness McIntosh of Hudnall: And what would you suggest it should be?

Mr Broach: We have suggested that it is amended to "Mental Capacity".

The Committee suspended for a division.

Q167 Mr Burstow: It has partly been picked up already, this question of the insertion of the word "personal" to "best interests" as the test and I think partly Stephen's question helped to unpick this a bit, that by putting the presumption of capacity at the beginning of our thinking does help clarify it in that "best interests" does not apply if you have got capacity. What I am still not clear about is if the tests around capacity apply and a person is found to lack specific capacity to take a particular decision or general capacity and then "best interests" applies, how materially for someone looking at the legislation and looking at any codes that are produced as a result of it would act differently if the word "personal" was there? What would be the specific things that would lead them to act differently? Is there any previous legislation where this has been used and, as a consequence, has a different effect? It really would be very helpful if you could give us some sort of sense of how this is not just semantics and is actually substance.

Mr Kramer: I will try to give an example to answer the first point. If somebody with a learning disability needs medical treatment and he lacks capacity to consent to that treatment, a decision on the medical treatment would be taken on the best interests. Although that person may not be able to understand

the nature of the operation or the consequences, you may be able to bring best interest factors that may bear on the medical treatment decision, for example, an individual who has a profound distrust and fear of needles and that fear and distrust of needles could be reflected in the medical decision-making process so that an alternative way of carrying out the treatment could be found. Actually the best interests about encouraging people to participate and taking account of past and present wishes could have a direct bearing on that particular medical treatment that is being proposed. Does that help at all?

Q168 Mr Burstow: No, it makes me more puzzled because in none of that did you use the word "personal" and, therefore, I want to ascertain how applying the word "personal" it would be different because the clause, clause 4, does, in (2)(c)(i), specifically talk about what you have just said, wishes and feelings, so that is there in the context of best interests, so can you help me one step further to understand how adding the word "personal" will make that list of things be read differently?

Mr Kramer: Because I think it would change the approach and the attitude to best interests because people would think in terms of the decision relevant to that individual, "What do we have to think about?" rather than thinking what is in the interests. If that person needs treatment, someone could say, "Well, that person lacks the capacity, so it is in their best interests to have treatment", and yet if someone who is involved with that person lacks the capacity to consent, how can we take account of past and present wishes. Actually if the terminology is changed and it says "best personal interests", it may think about the nature of the operation, thinking about the individual and having a much more person-centred approach to the treatment.

Q169 Mr Burstow: But is this not so much a question of the wording on the face of the Bill, but actually the codes of practice and the training that underpins it?

Mr Broach: Yes, it is, and that is absolutely crucial. However, we would like to see, as the Alliance, that it refers as many times as possible that it is about the person that is in the centre of the decision, so in that sense alone we think it is significant. It is also incidentally a recommendation made by the Law Society in terms of the technical question around other legislation which may include "best personal interests" which may be addressed to them. In terms of the checklist itself, there are, I think, some possible amendments and improvements that could be made. In 4(2)(b) the best interests test includes "the need to permit and encourage him to participate, or to improve his ability to participate", and that could be defined and unpicked further, I think. One of the things we would add in there is advocacy which I am sure we will talk about in more detail later on. We would argue from the very beginning there that improving a person's ability to

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participate in decisions may well involve an advocate actually working with them to support their communication.

Mr Kramer: Just in terms of personal interests, if it said “personal interests”, people would be more minded to think about whether that person has enough information to make a decision and whether people have the time and support to make a decision. Can we not move away from this feeling that someone cannot make a decision because they have not been able to do that in the past? It would mean less focus on whether a decision is reasonable in the interests of somebody else, so I think it is not just a question of terminology, but I think it can make a big difference in terms of how the Bill is applied.

Q170 Mr Burstow: The answers you have given seem to mix tests of capacity with tests of best interest and we need to make sure in the evidence that we are getting and the answers we are getting that we are picking those two apart so that we take the sequence in which they are being dealt with. It seems that you are conflating the two. Does that make sense? That is what it seems to me at the moment.

Mr Broach: That is a fair criticism and I think the fundamental point around “personal best interests” is that best interests could be looked at in a number of different ways and we want them to be looked at in the interests of the person in question and that is the reason we have made that recommendation.

Q171 Mr Bercow: I must say, I do not actually think we are greatly advanced or having much joy listening to the evidence you have given, but Paul Burstow beat me to it and posed the question which was very much in my mind. Presumably your problem with the concept is clear enough and, therefore, you want to make it in practice specific rather than unspecific, personal rather than amorphous, yet for all that, if you will forgive me saying so and this is intended to be constructive, it seems to me that the information does more to obscure than it does to clarify. In fact if we were to be persuaded that “personal” was not just a sort of emotional cushion, but something rather specific and practical, I think we would need more and better examples than what seem to me is the rather vague notion you have just advanced. I am sorry if I am being incredibly unfair or if colleagues think I am being very obtuse, but for me as a lay person it does not really advance matters at all. It is an additional word, but not an additional reason.

Mr Broach: There is an example, another one which may help. People with autism, many of them experience sensory oversensitivity. They are very, very sensitive to touch and may feel things far more sensitively than others do and, therefore, their treatment should take into account that sensory sensitivity. It is a similar example, I suppose, to Richard’s around the fear of needles, but perhaps a more general one for my client group. Therefore, in a general best interests sense it may be appropriate to treat them in a certain way, but you would want

to take account of their personal best interests and look at their personal circumstances which included this sensory oversensitivity and, therefore, a certain other type of treatment may need to be found.

Q172 Lord Pearson of Rannoch: I wonder if I could take you back to that category of people Mr Kramer referred to earlier with severe learning disabilities or mental health and, therefore, intellectual disability or impairment or handicap, whatever you want to call it. I think you indicated that changes in behaviour might indicate what people want. Of course that may be or may not be and it would depend on the individual, I suppose, but if we take clause 4(2)(d)(ii), it says, “In deciding for the purposes of this Act what is in a person’s best interests, regard must be had to (d) if it is practicable and appropriate to consult them, the views of (ii) any person engaged in caring for him or interested in his welfare”. In those circumstances, where do you put the family in the pecking order, as it were, if there were to be a disagreement between family members who cared for him and thought they knew him best and the professionals? Do you have a view on, all things being equal, whether the family’s views should come first or the professionals’?

Ms Morgan: Clearly if someone has profound learning disabilities, the family are usually their strongest advocate and the people who have their interests at heart, usually, and, therefore, they need to have a strong say. Also in our work we have looked at the needs of people with profound learning disabilities and their wishes can be also ascertained alongside people who know them well and also by finding ways of communicating through objects of reference, using a coat to say, “We’re going out”, that sort of thing, and using pictures, sometimes using sign language depending on the people themselves. What I think would be also important and I feel we will be talking again about later is that sometimes there is also a need for advocacy to balance out the interests of the person and the family if there is disagreement and that it is very, very often the family where someone has a profound learning disability who would be likely to be their focus.

Mr Broach: In terms of how the Bill would work in a situation where carers and professionals were in dispute, all of the organisations in the Making Decisions Alliance or the vast majority of these represent both carers and people with impaired capacity and one of our fundamental principles was that carers should have the right to be consulted in the decisions taken on behalf of the person they cared for.

Q173 Lord Pearson of Rannoch: That is family carers?

Mr Broach: That is right. If there was to be a dispute, then this Bill provides mechanisms, such as the court of protection, to resolve those disputes and it would be impossible to say that professionals or family carers should take the lead unless one of them has formal powers set out in the Bill such as the powers of a deputy or an attorney.

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Q174 Baroness Fookes: I was / unconvinced yesterday and I remain unconvinced today that the word “personal” adds anything whatsoever to the terms of the Bill, but I understand what lies behind it and your concern that the best interests should be secured, but it seems to me that your concern about the needles is fully dealt with under 4(1) and (2)(c), that past and present wishes and feelings and other factors which should be considered totally covers the question of how you dealt with a great fear of needles. Would you in fact be happier if there were a code of conduct or codes of practice attached to this which would perhaps expand on what we have under clause 4, the best interests, and, if so, would you be interested, willing or able to give some kind of outline, not right now, but have you given any thought to codes of conduct in any detail?

Mr Broach: Yes, we have. In terms of the detail of their contents, our focus has primarily been on the Bill to date and codes of conduct around best interests would be absolutely essential, and before that, as was set out in answer to Stephen Hesford’s question, a code of conduct and assessment of how clause 2 would be put into practice would be very necessary. I think that certainly some of the subclauses around best interests do focus attention again on the individual. If I could just pick up that point about past and present wishes and feelings, we could go back again to the evidence given yesterday about the need for advance statements to have significant priority in the Bill because at the moment they are just grouped in amongst other potential expressions of wishes and feelings and actually if they were in there, then I think the focus on the person may be delivered through that route more effectively perhaps than just the addition of a word to the test.

Q175 Baroness Barker: I too for the last couple of days, because of this word “personal”, have been confused, although I understand what you are trying to get at. However, I have a deep fear and I would like your reaction to it, which is whether it is conceivable that the inclusion of the word “personal” sets out on the face of the Bill an almost inevitable conflict between the individual and those around him. I listened very carefully to what Ms Morgan had to say, that people who live with people all the time who have limited capacity often are best placed to understand their function over a long period of time, but can you convince me that by trying to do well for these people, we are not setting up that conflict?

Mr Kramer: I do take your point that there is a difference of opinion in terms of the terminology and the impact it can make. I think just building on the previous question, what seems to be inseparable from the Bill is a change in attitude and approach which may need to accompany it. Yes, in terms of the term “best interests” it is in the Bill to take into account past and present wishes and other factors which would be relevant, but that is assuming that the Bill would be applied in practice and that will demand a change in terms of culture and attitudes. I

think that is why my last attempt to make the case for “personal” is that it will exercise the minds of people and help create an atmosphere to change the culture. We have agreed, I think, that we need to rethink it because we accept the points which have been raised by the Committee today.

Ms Morgan: If I can just add one more thing about “personal”, the White Paper *Valuing People* of 2001, a core part of it is person-centred planning, so for people with learning disabilities a personal-centred approach is really there in the culture and being developed in the culture and for that reason I think it is consistent. I know it is not legislation, but it is a policy paper and for this particular group I think it is consistent with what is said in that White Paper.

Q176 Baroness Barker: I would like to know, in your opinion, if the word “personal” did not appear whether the whole best interests approach should be abandoned in favour of the principle approach which was taken in Scotland? That is a big question, I know.

Mr Broach: It is, but could I just attempt to answer your last question one more time. Conflict is the point, conflict between interests, and how that fits in with best interests. That is precisely why we think that the word “personal” needs to be added because if there is a conflict, and in reality there are conflicts between informed people, the professionals and the person themselves, then it is the person’s best interests which should be at heart, so that is our final plea perhaps for the word “personal” to be included.

Q177 Chairman: Are you saying that if in fact the principles in the Bill and the codes of practice were extremely well drafted, that would meet your concerns?

Mr Broach: It is possible. We would want to think about whether essentially we prefer the Scottish approach or the English approach, bearing in mind this discussion. We will write to you on that.

Q178 Mr Burstow: Moving on to clause 6 of the Bill and the general authority, we took some evidence from the Alliance yesterday on this, but it would be useful perhaps just to build on that and seek some further clarification. We have had representations from some self-advocacy groups like People First and they have told us that they see the Bill as meaning that people with disabilities would be bossed about and controlled about even more than they are already and they go on to express concern about the fact that there appear to be no mechanisms for complaining about or challenging decisions which have been made on their behalf. In evidence we had last week from the Scottish Law Society, we were told that this would be used retrospectively as a justification for what has occurred. What do you think could be done to meet those concerns from People First and the concerns from the Scottish Law Society about the introduction of this wholly new idea of a general authority?

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Mr Kramer: The starting point in terms of People First's concerns is that I think there was some concern that the accessible version of the Bill in fact did not explain the term "general authority" which was an issue which has led to a lot of concern amongst self-advocacy groups, and they feel very suspicious about why an accessible version of the term "general authority" was not referred to, so that is one concern. The other concern is about being clear what the general authority is for and the parameters for that and I know that the people from the Scottish Law Society were concerned about the general authority *per se* and I think it would be useful to explore the case for the general authority and then perhaps to look at the safeguards which may be needed. Their concerns about people not having to justify actions at the time a decision is made, but only when it is challenged, we do share those concerns and that is why we think there need to be additional safeguards. Would it be helpful if I take you through the argument about why the general authority?

Q179 Mr Burstow: It perhaps would be helpful if you could say something about what the safeguards should be to allay that concern.

Mr Kramer: In terms of the need for a general authority to act, I think many organisations representing carers have been concerned that they are unsure about how to make decisions which represent the views of people who lack capacity and they want clarity about what day-to-day decisions they can make without going to the courts for formal authorisation, so the general authority is positive in the sense that it will dispel the doubts and confusion from carers about what they can do. What it does not do is really set out what the limits are to the general authority at all and that, I think, is the major concern that ties in with People First and the Scottish Law Society. I think the point is that when the idea for the general authority was set out in the Law Commission Report *Who Decides*, it was felt that it would actually give recognition to day-to-day decisions and that they would be distinguished from more formal arrangements for authorising decision-making and that some decisions which would be reserved to the courts and others taken out of the court system altogether and that this Bill does not really clearly set out the limits of a decision that can be taken under the general authority. Therefore, in terms of the safeguards, I am slightly reluctant to talk about terminology because of personal interests, but I think it should say the "general authority to act reasonably" is the starting point because that in itself sets out the safeguard of the basis on which decisions should be taken, which is reasonably. Yes, it does say that in the rest of the clauses of the Bill, but I think it is very important that it says that in the terms of describing the general authority and how it would work. Then I think the scope of the general authority needs to be more clearly defined in the Bill. Now, part of that can be dealt with in terms of codes of practice and that might be very helpful in terms of changing practice

in terms of carers and involving people in decision-making. Some other aspects are in terms of recording the general authority and recording decisions so that a person who is making a decision is able to justify the decision. That is particularly pertinent for care staff where there are already mechanisms whereby people can record decisions that they have made and, therefore, justify their decision. Another way of doing it is thinking about how can this Bill minimise opportunities for conflict and how can it maximise opportunities to reach agreement, and the problem is that the only way to challenge that general authority is to go to the court of protection, so other safeguards, such as recording decisions, looking at mediation and alternative dispute resolution, they are factors that provide extra safeguards. I do not know, Stephen, if you would like to add the specific restrictions that you want to see.

Mr Broach: Again I need to set this out in context. The general authority in this Bill attempts to do two things. It attempts to provide the framework for the day-to-day decisions that Richard has outlined. It also attempts to give an emergency authority and many of the questions yesterday focused on what would happen if the emergency authority was not possible. I think it is very important that those two aspects are dealt with separately because it may be impossible to do both in the context of the general authority. In terms of day-to-day decisions we want the focus to go very much back on to the sorts of actions and decisions that are set out in the explanatory notes, things like cooking someone breakfast, taking someone out for the day, those sorts of general everyday decisions, and we thought about it in terms of the significance of the decision and also the length of time that you have to make it, so if the decision is not that significant, it is reasonable to take it under the general authority regardless of time. However, if you have a really significant decision such as where someone lives, how they are going to spend their days and indeed medical treatment, it is not reasonable, in our view, for those decisions to be taken under the general authority unless there is a pressing need for it to be done so and that need is in the person's best interests, and in those cases if a decision is taken under the general authority, then the need to log them and record them so that the decision can be challenged afterwards becomes even more paramount, so there is a second set of circumstances which you may want to question me about.

Q180 Baroness Fookes: I have considerable sympathy with your view that the general authority is really much too general, but in addition to day-to-day decisions and emergency decisions, there is that range of major decisions which may not be emergency, but nevertheless have to be made, like a change of housing.

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Mr Broach: That is exactly right.

Q181 Baroness Fookes: This is, I think, what you are saying. How do you think it would be possible to frame the Bill to reflect this?

Mr Broach: Well, we have thought long and hard about this and what we have started off by trying to do was to create categories of decisions that should be excluded from the remit of the general authority. The problem with that of course is where do you draw the line and for some people decisions like that are much more significant than others. By actually setting out, for instance, where someone lives as a decision, it may be appropriate in certain circumstances, say, if a person has always lived with their family and their family moves house, you are changing the setting, but you are not changing the place that they live in terms of being in their family home, so it becomes very difficult to frame it in legislation and that is why we thought about significance and time as the two key factors which determine whether a decision under the general authority is reasonable or not. The other set of decisions we do want excluded are medical consent. We do not think that carers should be able to give decisions that amount to consent to medical treatment under the general authority and instead those decisions should be reserved to the medical practitioners, but the carers should be absolutely consulted by the medical practitioners which is the duty under the best interests.

Q182 Baroness Fookes: All medical decisions because it might be something very minor or it might be something exceedingly major and there is a great difference?

Mr Broach: That is right. It is consent that we have focused in on, so anything where the patient is required to give consent. It is also very important to remember that the general authority should not, must not and cannot apply to anyone who is not incapable, exactly as we were talking about in that best interests do not apply to anyone who is not incapable. Another restriction should be an absolute duty to look at whether the person has capacity and at the moment it specifically suggests that the general authority is subject to section 4, best interests, and we think that it should be subject absolutely to section 3, the presumption of capacity, and section 2, how capacity is assessed.

Q183 Baroness Fookes: If, for example, somebody had a verruca on their foot, it is not the same as having a heart by-pass, is it?

Mr Broach: No, absolutely. The other thing there is that the medical professionals in both of those situations would be able to take the decision because they have a duty of care and they would have a duty to consult the family that were involved if the person cannot and of course the person themselves even if they can or cannot give a decision. Our second argument is that those decisions taken under the general authority, because they have to be taken

quickly, should still be lodged with the court of protection so that they are officially recorded and can be challenged at a later date.

Q184 Mr Burstow: In the explanatory notes which you referred to just now, it gives some examples around "personal" where it might involve touching, not invasive medical intervention, but touching where consent cannot be given because the person lacks capacity. Are you saying that those are things which should not be subject to general authority, but in fact should be subject to some other process outlined elsewhere in the Bill?

Mr Broach: We made the distinction between routine medical treatment and consent for a specific treatment which is new to that patient, so if a routine medical treatment is to be administered, then that is appropriate to be given under the general authority.

Mr Kramer: That is making a distinction between the day-to-day care of somebody which would come under the general authority which you I think you were referring to and that would be the day-to-day work of support staff, the professional, in terms of looking after somebody who may lack capacity which would come under the general authority.

Q185 Mr Burstow: Therefore, from the evidence that your colleagues gave yesterday, the trigger for all of this would be a care conference?

Mr Broach: Absolutely.

Q186 Mr Burstow: I think the concern I still have, and I have not really heard you offer any reason why I should not continue to hold this concern, is that it is the informal arrangements, the arrangements which happen now and will continue to happen probably in ignorance of the law where no such process has been gone through at all. What do you think your proposals of having a trigger mechanism will do for those people? Are you effectively, by proposing a trigger, criminalising those people who will be taking those decisions?

Mr Broach: What we are trying to do is to expand on what "reasonable" means in the context of the general authority, so if a person was in a care home, it would be reasonable for a care conference to take place. If a person is cared for at home by their family and is not in contact with services, and this is very important for my client group because many people with autism are not in contact with any services at all, then it is reasonable for the carer to assess the person's capacity to the best of their ability, support them to make decisions, and to record that they are operating under the general authority so that if they are challenged, they can explain why they have made those decisions and in that context that would be reasonable.

Mr Kramer: Subject to that, informal carers are making decisions every day and they are complex and multiple about washing, feeding, dressing, what to do during the day, so we are not saying that each and every decision has to be recorded and each and every decision has to be separately justified with a separate assessment of capacity for each decision,

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particularly where those day-to-day decisions are very extensive, but what we are saying is that we hope that what the general authority will actually do is encourage the carer to think, "Well, how can I involve the person in the decision? How can I maximise the right of the person to make the decision that they are capable of?" So, if the general authority had the proper safeguards, it actually could enhance people's rights and not take them away from them.

Q187 Lord Rix: Did you consult with self-advocacy groups during your deliberations? They came along to your meetings.

Mr Kramer: Some self-advocacy groups such as People First decided that they did not want to be part of the Making Decisions Alliance largely because the Making Decisions Alliance campaigns for legislation and supports in principle billing legislation and People First do not, but we have had meetings with self-advocacy groups and, only last week, the Department of Health organised a meeting which brought together a wide range of people, professionals of different organisations and self advocates to discuss the Bill. I do think it is important that the views of self advocates and carers are engaged as part of the Committee's inquiries. I think it is important to hear the views of self advocates who are supportive of legislation and those who have concerns but, in terms of our work, we have tried to involve them.

Q188 Lord Rix: So, you think it would be advisable if we could possibly hear those witnesses?

Mr Kramer: Yes, absolutely.

Chairman: We are having People First, Changing Perspective and some other people as well.

Q189 Baroness Fookes: I am not quite clear as to when you are recommending that there should be a recording of the application of general authority and when not. You have mentioned that all the multifarious small day-to-day procedure need not be the subject of formal record, so where do you draw the line?

Mr Broach: What I think we need to come back is that anyone using the powers in this Bill should be able to justify them. So, if you are claiming protection of the general authority, you would need to be able to justify its use. That does not mean, as Richard has said already, that you have to justify that you used it on Thursday to take someone for a walk, but you would have to be able to explain why the person in your care is not able to make a decision for themselves, and then you have to be able to justify that your decisions are reasonable. So, it is about recording, to the extent that you feel necessary, information that will allow you to make that justification.

Q190 Baroness Fookes: Normally, recording means something written.

Mr Broach: Yes, but we are not necessarily making that argument. We are saying that the person making the decisions has a responsibility to justify that what they have done is reasonable.

Q191 Baroness McIntosh of Hudnall: Can I just ask you whether this would be a reasonable reclassification of what you said. Given that day-to-day decision making is not practicably subject to being written down, what you would presumably be concerned about is that, in the event of a challenge, anybody who has taken a decision on behalf of somebody who lacks capacity or is alleged to lack capacity can give an account of that decision.

Mr Broach: Absolutely.

Q192 Baroness McIntosh of Hudnall: Therefore, the responsibility on the carer is not so much to record their decision as to be aware of what decision they are taking.

Mr Broach: Precisely.

Q193 Baroness McIntosh of Hudnall: And to have a reflective ability to recall it later. Is that right?

Mr Broach: Yes and to be able to demonstrate an understanding of the principles that allow them to claim the protection of the general authority.

Q194 Baroness Fookes: In your written evidence, you suggest that the phrase "...or person reasonably believed that he lacks..." should be omitted. Could you justify that to us.

Mr Kramer: I think there was concern over the word "believed" because it suggests a lower threshold to reasonable grounds or reasonable judgment. So, there is a concern that the term "belief" by applying a lower threshold may mean that the need to assess capacity and support people to make decisions could be circumvented in some way. I think the term "belief" is the concern. It does not suggest an element of objectivity that is needed. One approach would be to omit the term at all and the other approach would be to bring a sense of objectivity by having reasonable grounds or reasonable judgment. We do think that "belief" has a different meaning in law.

Q195 Baroness Fookes: If it were to be omitted, would this not leave some carers in a very precarious position legally, particularly if they took some sort of emergency action or even, as was suggested yesterday, an accident and emergency department visit?

Mr Kramer: In terms of emergency actions by health professionals, I do not think it will affect that because a decision in an emergency would be made under a duty of care and it would be limited to interventions that will either prevent a deterioration or improve someone's health. So, I do not think that the term "reasonable belief" itself will have an impact on, say, a health professional's duty. I do not think it is the trigger point. I think a health professional will make an assessment and will make

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that act in their best interests. So, I do not think that the term “reasonable belief” in its omission or inclusion will actually affect that relationship.

Q196 Baroness Fookes: No, but it could certainly affect other carers in different situations, could it not?

Mr Broach: Our arguments on that would be that an assessment of capacity is no more than a judgment in any case and that we should be able to justify how we reach that judgment but, by including reasonable belief, it implies that in some way something else is absolute and we would take great issue with that.

Q197 Baroness Fookes: Would you be happier if it stayed in in what I might call a “beefed-up” form?

Mr Broach: How would it stay in in a beefed-up form?

Q198 Baroness Fookes: As you were the one suggesting that it should be omitted, I leave you to suggest how it might remain.

Mr Kramer: We suggest a beefed-up approach would be reasonable grounds/reasonable judgment because that is a much more objective approach than a subjective belief, so that would be an improvement in direct answer to your question.

Q199 Baroness Fookes: Obviously I would not hold you to it right now because I am asking you to do it off the top of your heads, but something of that sort would remove both your anxieties?

Mr Broach: It would send a clearer signal that it was not possible to use a general authority as a *carte blanche* which was what it was described as.

Chairman: You can always write to us afterwards if you have any ideas.

Q200 Stephen Hesford: May I just continue on that. Could you foresee a circumstance where a person had a reasonable belief that something should be done that they did not objectively believe or hold the view that they reasonably believed? What are the circumstances in which they would not themselves objectively hold that view?

Mr Broach: We are dealing with a client group who are born with conditions that will impair capacity in adult life, and carers of people who are born with a learning disability or with autism will have been with that person all the way through their childhood and into their adulthood and I think that many of those carers will not consider the possibility where, at 18, suddenly that person will be able to make decisions for themselves and therefore they believe it is completely reasonable to say, “I have cared for this person throughout their life and therefore I will continue to do so and I will continue to make decisions on their behalf.” We would challenge that. We would not accept that.

Q201 Stephen Hesford: If that were taken to its logical conclusion, that would not necessarily be a reasonable belief.

Mr Broach: Yes, indeed, the reasonableness of it would certainly be challenged, but we are asking for that problem to be omitted from the Bill.

Q202 Stephen Hesford: In law, the phrase “reasonable belief”, which is used a lot, is in fact an objective test.

Mr Broach: And, as was described by our colleagues yesterday, our concern is how the Bill will be used in practice in that carers may see themselves as being people such as, “I am a reasonable person and I believe that what I am doing is perfectly acceptable.”

Q203 Stephen Hesford: This is actually quite a tough test for a carer to undertake.

Mr Broach: Our position is that we would prefer a slightly tougher one.

Chairman: We will now move on to court of protection.

Q204 Lord Pearson of Rannoch: Do you feel that there are sufficient checks and balances on the face of the Bill in relation to the powers of court-appointed deputies?

Q205 Lord Pearson of Rannoch: Will the court of protection be sufficiently accessible to those with mental incapacity?

Mr Broach: I will take the deputies question first, if I may. Our colleagues yesterday outlined that the Bill was in accordance with the court of protection’s duty to investigate conflicts of interest when deputies are appointed. For example, if a care home manager was already the deputy for five of his residents and a sixth application was made, we would want the court of protection to investigate whether that was appropriate. We also want to see a clear link to the protection of vulnerable adults registers being established and Criminal Records Bureau checks. We have said very clearly in our written evidence that we do not think that deputies should be able to give authorisation for the withdrawal of artificial food and hydration, unlike our position on lasting powers of attorney because there the attorney is at least given that authority by the person when they have capacity. Those are the points that were made yesterday, but I would like to make some additional points. Firstly, our experiences we have seen so far in Scotland suggested that families are being encouraged perhaps to apply for wider powers than they need because it is seen to be more convenient for deputies to be appointed across a very wide set of grounds. The Bill itself precludes that at 16(4) but we want to make sure it is very clear in guidance that the deputies should only be appointed with the narrowest possible remit and indeed for the shortest possible time, if that is appropriate for the person. An area that was not touched on yesterday at all was appointeeship and, with the Bill creating deputies to deal with a person’s finances, we then have potentially the double situation where appointees exist governed by a completely separate set of regulations to those who are managing a person’s affairs as a deputy. So, we think that appointees

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should be brought in to the scope of this Bill. Our final concern around deputies is that the borderline between the general authority and the occasion when you would apply to become a deputy is very unclear at the moment because, with the general authority being so broad, we do not really see many situations where a family or carer would feel the need to apply to become a deputy. That is a problem which is again a reason why the general authority needs to be more circumscribed.

Chairman: We will now move to withdrawal of treatment. I am sure you will not be surprised to learn that we have received an enormous amount of evidence and submissions and letters on the whole subject of withdrawal of treatment, past directives and past orders etc.

Q206 Baroness Knight of Collingtree: Up until now, we have been dealing with people in whom you are interested when they are well and in normal life environment. Can we move on to the question of when they are ill. As my Lord Chairman says, we have had an enormous number, almost an unprecedented number in my experience, of letters expressing concern on this matter. Do you agree that the definition of “medical treatment” should include the provision of artificial nutrition and hydration? The nutrition and hydration is not the artificial part, it is conveying the nutrition and hydration. Do you see that that should be medical treatment or not?

Mr Kramer: We are going to repeat very much what was said yesterday in terms of, is artificial nutrition and hydration medical treatment or not? The view that was expressed yesterday and indeed we are giving today is that it is medical treatment and that you make a distinction between that and basic care. We also acknowledge that decisions on withdrawing artificial nutrition and hydration raise very difficult ethical personal issues and there are points of views and I know that the Committee have received huge representations. So, decisions on withdrawing artificial nutrition and hydration in cases where somebody lacks capacity are decisions that need to be taken very, very carefully and that, in circumstances where there is a complete inability for someone to have any physical or emotional experience at all in terms of their function of the brain where there is no activity in the cortex, so that their brain is not functioning in terms of understanding and interacting with their environment, and where there is no prospect of recovery at all, then the safeguard is needed in terms of withdrawing artificial nutrition and hydration. I think the point that has been made by the Scottish Law Society and by the MDA yesterday is the concern over this issue having undue prominence in the discussions on this Bill when this Bill is about principally supporting people to make decisions. In any event, I think it will strengthen the right of carers to be involved in medical decision making, strengthen the right of the individual to do so and make sure that health professionals are more accountable for the decisions which they are making, which I think is in the interests of all parties

because health professionals not only expect their decisions to be reviewed but they also want to have greater certainty in terms of the decisions they do make.

Q207 Baroness Knight of Collingtree: That is very clear except for one point that you raised. I was a little surprised that you feel that the decision as to whether or not a person wished to live was a rather minor decision. I would have thought it was a major decision.

Mr Kramer: I do not think I have said that. I accept that these decisions are very, very serious. We are dealing with decisions on withdrawal of artificial nutrition and hydration. I think that they are very, very serious decisions and that they need very serious decision making, but they are seen by the MDA as a medical decision.

Q208 Baroness Knight of Collingtree: Yes and that was the question I asked you. Now I would like to ask whether you think that it should be classified as medical treatment when a patient is able to take food or water in a normal way. Should the ordinary business of eating be called medical treatment?

Mr Broach: I think we would refer you back to the answer that was given yesterday.

Q209 Baroness Knight of Collingtree: I am very interested in what was said yesterday but I am more interested at the moment in what you say.

Mr Broach: Our position is that basic care, which includes provision of food and fluids by normal means if you like, should not be covered by advance directives and by lasting powers of attorney—that was the position that was given yesterday—and that therefore that they do not constitute medical treatment.

Q210 Baroness Knight of Collingtree: Do you think that the provision of basic care such as foods and fluid be excluded from the scope of an advance refusal or from the powers of attorneys or deputies to refuse treatment?

Mr Broach: Yes.

Q211 Baroness Knight of Collingtree: Finally, I would like to ask you this and this is a very important question indeed. In what circumstance might you consider that starving a patient to death through the withdrawal of artificial nutrition and hydration would be in that patient’s best interests?

Mr Kramer: I think I have set out the criteria in terms of when the decision of withdrawing artificial nutrition and hydration would be taken in the best interests where there is complete inability to have any physical emotional experience whether in the present time or in the future because there is no activity in the cerebral cortex and there is no prospect of recovery. Subject to that, the health professional will have to make that decision and seek second opinion for making the decision.

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Q212 Baroness Knight of Collingtree: You will be aware that there are now in production by some groups cards like donor cards which state perfectly clearly that the patient, if unconscious, still wishes to be given facility to live insofar as he or she can. Would you allow credence to be accepted on a donor card like that?

Mr Broach: Yes and I think that is a very helpful point to make because we are answering today for people who were born with incapacity and who cannot plan for their future incapacity. If you have capacity and you wish to make a positive advance statement of that sort, much as you are able to make an advance refusal, then you should be able to do so and we think that the Bill should include advance statements such as request for treatment, which is the point that we were making earlier.

Q213 Baroness Knight of Collingtree: I can only say that I am grateful for that reply but the question of best interests is not quite the same as was covered in the first point. As regards the question of a person being starved to death or dying from lack of liquid, it is very difficult to imagine any circumstances when dying of thirst could be actually in the best interests of the patient concerned.

Mr Kramer: Inevitably on these issues because there are huge ethical, moral and personal interests, one's personal perspective does come into play and I think that is why people have different views. In terms of technological development, it is possible to prolong someone's life indefinitely through artificial nutrition and hydration, even where there is no prospect of recovery and even where there is no activity in the brain. That is why decisions on withdrawal of artificial nutrition and hydration are important and that is why there need to be important safeguards, but there is a concern about artificially prolonging someone's life, prolonging someone's life in an artificial way, and not allowing people to die naturally. That is my personal perspective. I know that Hazel will want to give another personal perspective, but I think it is important to listen to different views.

Ms Morgan: The issue of safeguards is of enormous importance. We are talking about people who are very, very vulnerable, incapacitated and possibly unable to make decisions. My perspective comes from a personal one because my son actually received nutrition and hydration through peg-feeding in the final months of his life, he having been born with learning disabilities and having had severe strokes. So, I am speaking personally here. It is of the utmost importance that people with learning disabilities and people who find themselves in this situation have sufficient safeguards in order that their lives are not put at risk, and I do have a very serious concern about this for obvious reasons. I also would like to make the point that there are quite a lot of people with severe and profound learning disabilities who live with peg-feeding and I think there is a danger that we are thinking about dying rather than about living and I do think that this is also an important issue. My son was able to live for

another 11 months with this feeding, it was not withdrawn, and we enjoyed life together during those months. So, I think there are some enormously important issues and that safeguards have to be very, very, very, very tough.

Mr Broach: Just to bring us back to try and give the whole MDA perspective because obviously you heard the group yesterday and us today. The key answer to the question, "When would it be in the person's best interests to have the nutrition and hydration withdrawn?" is, "When they have expressly wished it to be so when they had capacity." So, that is an absolute position of the Making Decisions Alliance. In terms of our group, the issue is far more complicated because people are unlikely to be able to make those decisions for themselves. However, having said that, there will be many people within our groups who can express their wishes or feelings in advance statements and perhaps potentially even in advance directives and I think it is really important that we do not lose sight of the need for positive advance statements on medical but also on other issues because I think they are a very valuable way of recording a person's wishes and feelings.

Q214 Chairman: I am a little puzzled about the distinction that has been made between the artificial provision of nutrition and hydration and the natural provision. Is the answer in the answer which your colleague gave of activity in the brain? Clearly, if you are able to take food and to eat naturally, there will be activity in the brain presumably. Whereas, if you are being artificially fed . . . What is the logic behind the distinction between the artificial provision and the natural provision?

Mr Kramer: As a non-doctor, I will try and answer that question. My understanding is—and, please, do correct me if I am wrong—that somebody can receive artificial nutrition and hydration for a short period of time. They may go into hospital for problems with their stomach and they need artificial nutrition and hydration for a short period of time and that may actually benefit the individual. Artificial nutrition and hydration is not just provided in those end-of-life situations where somebody cannot function in terms of their brain and there is no prospect of recovery. It can be used as an intervention at earlier stages.

Q215 Chairman: I have someone in my family with motor neurone disease who was fed and drank artificially for something like a year but his brain was still active.

Mr Kramer: My personal experience is of somebody who was receiving artificial nutrition and hydration but chose—he had the capacity to do so—not to do so. He could have gone home and he would not have died immediately but his health would have badly deteriorated. He took a decision—it was his decision—that he felt that his quality of life and his meaning in life would have been better if he did not continue to receive that artificial nutrition and hydration. From my limited experience—and this is

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again from very much a personal perspective—it is not death that is a fear for people but the process of dying and the difficult experience through that.

Baroness Knight of Collingtree: Could I clear up one matter very quickly because it was brought up twice yesterday and has been brought up today. The House of Lords accepted last Friday in giving a third reading to a Bill that said any person who asked not to receive artificial nutrition and hydration should not have to do it. So, can we move that point out of any future discussion because that is agreed on every side.

Q216 Mr Bercow: I think I am clear about Mr Kramer's answer to Baroness Knight, but I would like to do more than think, I would like to be certain, so let us establish this for the avoidance of doubt. If someone gives advance notification that he or she definitely wishes to have his or her life prolonged by artificial hydration or if someone gives no indication either way, he or she, as far as you are concerned, should receive absolute protection. Certainly that would be my instinctive view, am I clear that that is yours?

Mr Kramer: That is a good question. If the advance directive is not clear and does not mention artificial nutrition and hydration, then the decision will be best interest and involvement of the individual or those close to him. The harder point to your question is this, if it is specifically mentioned in an advance directive and whether it has to be followed in all circumstances. I think—and this is my personal view—that it would be possible for a doctor to review that decision where the alternative is artificially prolonging one's life when there is no prospect of recovery in the terms I have suggested.

Q217 Mr Bercow: I must say that, having felt momentarily uplifted by your previous replies, I am really very anxious now. That is not your fault but it seems to me that we are in danger of moving away from the primacy of the ethical principle towards the triumph of administrative convenience and, dare I say it, even considerations of the money men at the Treasury. That is what worries me about this. What I am getting, Mr Kramer, is that, first of all, advance notification you fear . . . Perhaps I should not use that evaluative term. Point one, advance notification you suggest will not be an absolute protection. Point two, since you referred to considerations of family members, can I put it to you that the person who is the most vulnerable of all is a person who might well have given advance notification but who has no close family relatives and whose earlier judgment is likely to play very much second fiddle to the current view of a particular doctor.

Mr Kramer: Yes. If it is in someone's advance directive, it will have to be taken into account. What I am saying is not that a doctor will see the decision to say, "I want artificial nutrition and hydration in any event" and the health professional says, "I am

going to go back on that" because that cannot be done, but there needs to be a time of review of that decision and, if those safeguards are met where there is no prospect of recovery and there is no activity in the brain, then I think that, in those circumstances, it would be permissible to say that the right to artificial nutrition and hydration on an indefinite basis is not absolute.

Q218 Mr Bercow: You would be content with that?

Mr Kramer: This is again my personal view so, please, do correct me. I would not want you to think otherwise. The power at consideration is to give respect to that individual's views and, if that is reflected in advance, that should be reflected in practice. However, there has to be a decision in terms of what is in that best interests and whether it is in the best interests of a person to keep someone artificially alive in circumstances that I have suggested where there is no prospect of recovery etc. I think these things are very difficult and do need to be resolved in a proper way in terms of a second opinion and maybe a decision of the court of protection, but I would not be uncomfortable in saying that there should be a right to keep people alive indefinitely when there is no prospect of recovery and there is no activity in the brain.

Mr Broach: I think we need to clarify what the Bill says because the Bill at the moment only provides for advance refusal to the treatment which are absolute statements unless they are undermined—

Q219 Chairman: We are coming on to that.

Mr Broach: We would argue that there does need to be provision for positive advance statements on the face of the Bill, but the defence is that you cannot select treatment, you can only consent to treatment that is offered to you. That is the argument that has been put to me as to why advance statements cannot have the same level of authority in the Bill as advance refusals have, and that is a legal point which I do not have the answer to but that is the argument that has been made.

Ms Morgan: The MDA has said it is generally applied. It is so difficult to get a common view because it is such an emotive and difficult issue. For people who are judged to lack capacity, there is a real, real danger here that decisions are going to be made and it comes back to the best interests point and to think very much of the best interests of that person/individual in that situation. Where there is no hope of recovery is a very broad phrase. There can be limited recovery and sometimes there can be recovery so that the artificial nutrition and hydration is not necessary. Sometimes, people with profound learning disabilities who receive artificial hydration and nutrition can live for many years.

Mr Kramer: Yes, but we need to be very specific in terms of the safeguards. I take your point. You are not bound to detect a difference of opinion.

Ms Morgan: No, but I just wanted to clarify it.

Q220 Mr Bercow: It would not be a scandal if there were!

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Mr Kramer: If there is absolutely no prospect of recovery, where the functional aspect of the brain is not working, where there is a part in the brain that is pumping your heart and keeping you alive but there is no awareness of your outside experiences and where there is no prospect of recovery and there is an inability to interact with others and have a physical or emotional experience, then it would be right to make a decision in terms of withdrawing artificial nutrition and hydration, subject to all the safeguards in terms of how decisions are made and second opinions. Hazel's point is that decisions on treatment should be based on the gravity of the illness and not the degree of the disability and I think that is a very important issue in terms of quality of life decisions and ensuring that different standards or different assumptions are made and ensuring that different standards of assumptions are made because of someone's disability. I think that is a very important point that I share with Hazel.

Q221 Jim Dowd: We are in danger of confusing a number of different elements here. The case of advance refusals will really only apply to people who have had capacity at some stage.

Ms Morgan: Absolutely.

Q222 Jim Dowd: Most of the people you represent today will never have been in that position, so cannot be regarded in the same way. To pick up my Lord Chairman's point on what is the difference between artificial or non, is it not the existence of a degree of choice? If people can take food and nutrition by traditional means, they equally have the choice to refuse it.

Mr Kramer: That is right, yes.

Q223 Jim Dowd: It is when that choice disappears that it becomes artificial.

Mr Broach: And again the point was made yesterday that basic care includes the ability, if you can, to take food and water/hydration by natural means. So, we are following the existing guidelines that the British Medical Association have published.

Q224 Lord Pearson of Rannoch: I have been put a problem by a legal friend whose reading of the Bill is that lasting attorneys and deputies will have no clinical duty of care under the Bill so long as they act within their given powers, so they cannot be sued even if their decision could be clinically negligent if made by a doctor. I do not know if you would agree with that but, if so, does that put a patient who suffered damages in those circumstances in a position where he would have no legal remedy and no compensation in the courts? Is that your understanding of the Bill?

Mr Broach: I think I may have to say that we are not competent to answer that question. It would be a very interesting question that perhaps the Law Society might like to consider.

Ms Morgan: I could not answer, but we are saying that these kind of decisions should be outside the remit of deputies.

Q225 Baroness Fookes: If it is decided by those who have authority to act on behalf of the incapacitated person that artificial nutrition and so forth should be withdrawn, is that not a decision that ought to be taken finally by a court and only by a court?

Mr Broach: Not if the person in question has granted the power to make that decision to another person while they have capacity.

Q226 Baroness McIntosh of Hudnall: I am very sorry but I am getting extremely confused here because my understanding is that you are representing as part of the Making Decisions Alliance people who are born with some lack of capacity.

Mr Broach: Yes.

Q227 Baroness McIntosh of Hudnall: And indeed many people who were born with no capacity to make decisions. Am I right?

Mr Broach: We are here representing organisations who represent people who are born with a condition that may impair their capacity and, to go back to a comment made by Jim Dowd, many of the clients we work with will have capacity to make decisions. So, it is those who are born with conditions that may affect their ability to make decisions, which is why we are still able to and have a duty to comment on issues such as lasting powers of attorney and advance directives.

Baroness McIntosh of Hudnall: In which case, I will withdraw at this point and come back to it.

Q228 Lord Rix: Can I come back to what Hazel Morgan had to say about the word "recovery". What is meant by recovery is open to debate. Would you like to see a different phrase used rather than the word "recovery", if a phrase can be found?

Ms Morgan: I am thinking hard about this one. I am not going to answer your question directly, but I think that if someone has the capacity to enjoy their life, that should be respected. That is the right to life and I am again expressing a personal view. I think that recovery is incredibly difficult to define.

Mr Kramer: Can I try and answer and I may regret trying to make a stab at it as I have a few times today. I think your particular issue is about aspects of quality of life and perceptions of health professionals about someone's medical state and, if you are going to apply quality of life criteria, they really should be applied to a person with a known disability in the same way as a person without a known disability. People value and enjoy their lives in different ways and they may enjoy lives in ways which we would not choose for ourselves, but a consideration of quality of life is only relevant in terms of thinking of the gravity of the illness and not concerned with the nature and degree of disability. So, a decision to withhold treatment on that ground would be a clinical decision on the grounds that treatment would lead to pain and suffering which is disproportionate to any benefit. On that basis, the test should be whether the physical survival of the person is in their best interests and whether

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somebody could make something of their life in the context of their life within their existence defined by their disability. So, doctors should compare the condition of the individual before treatment with the expected condition after treatment and they should be considered relative to each other, rather than comparing the state of a non-disabled person to a disabled person. What I am trying to say is that, in terms of medical decision making, the nature of the disability or the degree of disability is not a factor, it is the context of the gravity of the illness. I do not know if that is answering your question.

Q229 Lord Rix: It is.

Mr Kramer: I am trying to expand perceptions in terms of quality of life which Hazel was talking about earlier.

Lord Rix: I hope that has given all of us food for thought.

Q230 Baroness Barker: I have found this extremely helpful because this is a subject on which there is a great deal of emotion which I find quite distressing. It has been enormously helpful to me to realise that the focus is on the decision at the point at which it is made and that all subsequent decisions which are decisions about treatment of any sort have nothing to do with a person's capacity at all. The question I want to ask you is, if you look at Clause 23 of the Bill, do you agree that there should be a presumption that a person has capacity to make an advance decision and that, once that person has made an advance decision, that should be treated with the same regard as anybody else who has made an advance decision?

Mr Broach: We would have to agree that because otherwise it would undermine the presumption of capacity.

Mr Kramer: Your point that these issues are not to do with capacity is central and extremely important.

Baroness Barker: That is correct and I found it very helpful when your colleagues yesterday talked about advance statements to have treatment as well as the withdrawal of treatment. I think those have thrown a great deal of light on the issue we are talking about.

Q231 Baroness McIntosh of Hudnall: Allowing for the fact that I have been struggling a little with this and I am a little confused, the questions that I wanted to ask you are about the issue of human nature which hangs rather uncomfortably around these questions of advance directive and withdrawing of treatment. Do you have a view about the concerns which have been voiced extensively to us by a number of groups that the provisions in the Bill for lasting powers of attorney and for an advance directive to refuse treatment do amount or could amount to the permitting of euthanasia by neglect?

Mr Broach: Yes, we do have a view which is again the same as the view expressed yesterday, which is in summary that what the Bill seeks to do is give the same rights to people who can plan for their incapacity once they are incapable that they enjoy

now. So, euthanasia is something that only those who have the capacity can do, and what we are talking about here are people who lack the capacity to make the decisions for themselves. Really, what it boils down to is that the argument around euthanasia I feel personally is a bit of a red herring because really what the argument is about is whether people should be able to opt out of treatment including withdrawal of food and hydration and that applies whether you have capacity or you do not have capacity and that is the argument we were making yesterday.

Q232 Baroness McIntosh of Hudnall: I am not sure that I entirely understand that because, in order to opt out of the treatment, you have to have had the capacity to understand that that is what you are doing.

Mr Broach: Yes and that is what you are doing by making either a lasting power of attorney and including those powers or by making an advance refusal.

Q233 Baroness McIntosh of Hudnall: That is correct. It is my understanding that the issue that is being put to us is that by allowing people at the point at which they had capacity the right to make an advance directive of that kind—and this would be particularly true with the vulnerable group of people where perhaps there might be a greater need to establish capacity or incapacity—that then subsequently for that advance directive to be implemented in relation to such a person could be construed as a form of euthanasia by neglect. I do not advance this as my view but I simply say that it is—

Mr Broach: Our view is very different in that what we are asking for is a right for people to plan for their future incapacity and that, if an advance directive is not appropriate, then it will not be implemented if it is not valid or applicable. There are various safeguards in the Bill around advance directives, so they do not have absolute status. For instance, if a new treatment comes along that was not available when the person made the advance directive, it would no longer apply and the MDA supported those safeguards.

Q234 Baroness McIntosh of Hudnall: That leads me to my second question which directly relates to that point, which is that medical advances are happening all the time. It might be thought that it was not wise to enshrine anything of this kind in legislation when the likelihood of an advance or indeed simply change, whether one construes this as advance or not, is very high and it should be left to the courts. Do you have a view about that?

Mr Broach: We do not as an Alliance have a view on that but my personal perspective on that issue is that the legislation does provide a degree of flexibility as I have just outlined and that actually this issue is of such magnitude that it would be better dealt with in the statute and I do not think anyone here will

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disagree with me. I think these are issues on which we need to go back with colleagues and perhaps we could write to you.

Q235 Chairman: Are your views affected at all by the evidence we have had which is strongly felt by people who have a deep moral and religious belief that even if in fact somebody wants to have advance refusal of treatment, they should not be allowed to do so because it is morally wrong?

Mr Broach: I would argue that. As an Alliance, we support the right of people to plan for their incapacity and to make those decisions. I would also like to point out that over 7,800 postcards were sent to the Lord Chancellor by supporters of the Making Decisions Alliance in favour of our position on mental incapacity legislation. So, there is a substantial body of support for our line on this Bill as well as a body of support against.

Chairman: Do not suggest that they send a thousand to us!

Q236 Jim Dowd: Probably as contentious as withdrawal of treatment in past directives, would you give your view on the Bill's status *vis-à-vis* the Human Rights Act and Article 2 of Schedule 1.

Mr Broach: As again stated yesterday, we see Article 2 as a right to life and we acknowledge the duty that public authorities have to preserve that right and protect that right, but we feel we should be able to choose not to take up that right and therefore, in that context, we feel that advance refusals are not contradictory to the Human Rights Act.

Ms Morgan: I would like to be very sure that the right to life of people who lack capacity is not threatened, undermined and damaged by this Bill.

Q237 Jim Dowd: Do you think it will be?

Ms Morgan: I think, for example, if deputies can make a decision regarding withdrawal of treatment, the decisions need to go to court and be very, very seriously considered. I think the withdrawal of nutrition and hydration is a very painful experience and that, if people choose to in their advance directive, that is one thing, but to assume that for someone who does not have the capacity undermines their right to life.

Mr Broach: That is right and, in our written evidence, we have said that deputies should not be able to make that decision. There is another point in the Human Rights Act which we would like to make note of in relation to a different article: Article 8 and the right to respect for a private life. I think this goes back to the very first point I made at the beginning of this submission that our concern is that powers in the Bill may become applicable to people whose capacity has not been actively assessed. An assessment is not defined in the Bill; it is not in the list of definitions. Obviously, how someone is incapable of making decisions is set out as a test, but there is no mechanism in the Bill for that test to be actually applied. There is provision for a code of practice on assessment which is one step forward, but there is a real concern that if powers in the Bill

did apply to people with the ability to make their own decisions or to make some decisions but not others, then that could well, in our view, contravene the spirit if not the letter of Article 8.

Q238 Jim Dowd: But that would be entirely subjective and would depend on the circumstances of the case.

Mr Broach: It would indeed.

Q239 Jim Dowd: It would not be an integral part of the Bill.

Mr Broach: That is correct, but to not at least define assessment within the Bill and give some indication of how the test of capacity should be applied we think is a mistake and omission, and in fact I think Hazel did come up with some words that might serve as a definition of assessment in the context of the Bill.

Ms Morgan: Yes. Assessment is clearly in the Bill and yet it is not defined very closely and I suggest that maybe this could be a possible definition, "A process whereby an individual's ability to make a decision in a specific area at a material time is determined and recorded by appropriate people/professionals who know the person, professionals from a range of background, so that the medical and social models are acknowledged, depending on the area of decision making, with the person who is judged to lack capacity also involved along with their supporters or advocates."

Ms Clipson: If we could make the point about advocacy now, we think it is very important and I think we have raised in our submission the issue about how advocacy in many of these things we have discussed today could be very useful in preserving the rights of people in this position and helping with the empowering and presumption of capacity issue by clarifying whether people have capacity. So, for example, in the assessment process, having access to an advocate would be very helpful because most of the people I talked about at the beginning who might have problems with communication and making it clear that they have such capacity and in fact, in some of the issues we talked about in terms of major life-changing decisions, we recommended that there should be an access to advocacy in those instances because they are such an important part of people's lives.

Baroness Knight of Collingtree: Do you recognise that one of the grave concerns about this matter springs from the fact that, within living memory, other governments in other countries have decided that mentally handicapped people ought not really to be here at all and that something must be done about that? Do you recognise the danger that there is so frequently, particularly in the elderly who can easily be made to think that they themselves are a burden to their relatives and ought to be asked quietly to be got rid of? Do you recognise that that is a very real worry which undermines many of the letters that we are receiving?

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Q240 Baroness Barker: Can I ask a question which follows directly from that and relates in fact to what you said. For some of us, the empowerment of individuals is an extremely important principle and one of the important principles of that is the principle that there should not be presumptions made against people in advance. My question to you is this: in putting forward proposals on assessment, which I would like you to come back to at a deferred stage, would you consider within that the issue of consent to assessment? I know that is not so pertinent to many of the people whom you are representing as it was to people yesterday, but there are key issues about people having capacity and moving to a state where they do not have capacity and that part of their transition is very important to them to maintain and to not have intrusions from the State because where I have profound disagreement is that it is always important that the individual is empowered above the State in these matters. So, could you take that and add that into the independence of advocacy services.

Mr Broach: Yes. We are dealing with the most vulnerable group of adults in our society and we are dealing with a historic legacy of treatment for those adults which we have dealt with in the initial statement which does not meet with our expectations today and, yes, there will be the possibility of abuse in this legislation and that is why we think that the highest possible number of safeguards need to be placed on it. Then of course accusations are made about bureaucracy, but we think that the right to the person to make their own decisions and the person's interests should be paramount. So, absolutely we acknowledge the concerns that people will be pressurised or forced into doing something that is against their will within the context of this Bill. However, it provides for that and indeed there is a criminal offence that relates to it and there are provisions in the general authority particularly around the use of force that is completely unacceptable. In terms of the need for

independent advocacy, that is again absolutely central to our concern. We are all here trying to balance the interests of carers and the people with disabilities or other conditions, and hopefully the majority of cases their interest will be in line but there are many instances where they are not in concord. It is not just the statement, you have to worry about family disputes and tensions and, in that context, independent advocacy is absolutely essential.

Q241 Baroness Barker: That is why the issue of consent to assessment, which nobody else has talked about, I think is very important and I would like you to think about that.

Mr Broach: It will be interesting for our group too because there will be people who are very vocal, very verbal and very articulate and able to say that they do not want their capacity to be questioned or challenged and, to an extent, that right should be respected.

Q242 Lord Rix: There was some wording in the Journal of the Royal Society of Medicine which was quite useful. Would it not be helpful if this decision to make living wills official, as it were, be in the guidance of the Bill with the appropriate wording which will be not capable of getting misconstrued?

Mr Broach: Absolutely. Guidance in this Bill will be absolutely essential and that will be one of the key aspects to it.

Chairman: I am afraid that we are now technically inquorate because we require a certain number of Members of both Houses to be present. I was about to suggest anyway, as we have been going now for two hours, that we finish there. You have mentioned advocacy and I think it would be extremely helpful to us if you could put something in writing about the importance of advocacy and how you see it working. As regards the questions, which you have seen but which we have not reached, could you reply to those in writing. May I conclude by thanking you very much indeed for a most helpful session.

5. Supplementary memorandum from the Making Decisions Alliance (MIB 1188)

The Making Decisions Alliance was asked to submit additional written evidence to the Joint Committee following our oral evidence session. We were asked to respond to specific questions raised by members of the Committee and to answer some of the written questions drawn up by the Joint Committee.

1. BEST INTERESTS

The Joint Committee specifically asked the MDA whether it favours the best interests approach in the draft Bill or the general principles contained in the Scottish legislation.

The Scottish legislation has some general principles at the beginning of its Act that set the tone of the legislation and ensures that any intervention brings a benefit to the person and is the least restrictive form of action. The Mental Incapacity Bill also contains some principles, such as the presumption of capacity and the need to ensure that decisions taken on behalf of people who lack capacity are taken in that person's best interests. The Mental Incapacity Bill has additional safeguards around assessment in terms of how people should or should not fall under the powers of this Bill. In particular clause 2(2) states that, "A person is not to be treated as unable to make a decision merely because he makes an unwise decision". The MDA believes that it is essential that the Bill maintains the balance between respecting the right to autonomy (presumption of capacity) and the need to ensure adequate protection for those that can't make decisions (best interests).

Currently, the Bill is weighted in favour of the latter. The MDA is concerned that the emphasis on best interests in the Bill as drafted may lead to a misunderstanding that the overriding aim of the Bill is to impose or restrict a person's own ability to make decisions.

The MDA would favour an approach that would strengthen the existing principles in the Mental Incapacity Bill and clarify more clearly the right for people to make decisions that they are capable of making and for people to be supported to make those decisions. We recommend that the presumption against lack of capacity should be set out in clause 1 of the Bill. The Bill should also be named the Mental Capacity rather than the Mental Incapacity Bill and the clarification of the person's right to make decisions should be set out in the long title to the Bill. Clause 4 (1), which introduces the best interests criteria, should also state "that a decision shall not be taken on behalf of another person unless that person is incapable of making a decision on the matter in question; (b) a person shall not be judged incapable of making any decision unless all practical steps have been taken to assist him without success."

The MDA believes that that best interests is the right approach and the most appropriate guidance to making decisions on behalf of people who lack capacity. However, we still remain concerned about the term "best interests" as it is publicly identified as the phrase used in courts of law to determine the right of medical practitioners to make decisions on patient treatment. We believe that a new term is needed which does not have the same legal implications as best interests and which clearly distinguishes the right of health professionals to make decisions from the broader scope of decision making in the Mental Incapacity Bill, which would allow for the opinion of professional workers and family carers to be considered where appropriate. The term personal best interests would emphasise that priority should be given to identifying those issues most relevant to the person and to take account of their wishes rather than those of the decision maker.

2. GENERAL AUTHORITY TO ACT

The MDA envisaged that the general authority to act would give statutory recognition of ordinary day-to-day decision making by parents and others who have to make decisions for people who are not able to make their own decisions. This would be distinguished from more formal arrangements needed for authorising major decision making about people's health, welfare and financial affairs, with some key decisions being reserved to the courts and other decisions taken out of the system altogether, such as marriage and voting. MDA contends that the scope of the general authority is too wide and does not distinguish between different types of decisions. We regard the significance and timing of the decision as the two key factors that determine whether a decision under the general authority is reasonable.

The MDA's written submission to the Committee proposes additional safeguards in relation to the general authority to act in relation to medical decision-making and other significant decisions that amount to a material change of circumstances, such as a change of carer.

We also believe that it is important to consider what is reasonable in the context of decision making under the general authority. The MDA would argue that a health or social care professional acting under a general authority to act reasonably must have regard to their own professional codes of practice, including a person centred plan or care management plan and to be able to justify decisions taken on behalf of a person who lacks capacity. It would be reasonable to expect a professional carer to hold a case conference before making significant decisions. It would also be reasonable to expect a family carer to record why a decision was taken to the extent necessary to justify that the decision was reasonable, if challenged at a later date. For a proposed mechanism on challenges, please see section 5 (Court of Protection).

3. ADVANCE STATEMENTS AND REFUSALS

The MDA strongly recommends that the Mental Incapacity Bill include provision for advance decision-making. Advance statements (which are statements of wishes) and advance directives (which are advance refusals of treatments) should both be provided for on the face of the Mental Incapacity Bill. It would allow specified treatment to be carried out or continued.

An advance statement would specify the types of treatment that a person would or would not find acceptable in certain circumstances. They could also include decisions about where they want to be cared for whether in their home or in a specialist residential home. The ability to state their wishes in advance can reduce a person's anxiety about the future, and give people reassurances that their wishes will be taken into account. This would not of course oblige doctors to use treatments they considered inappropriate. We were very much encouraged by the Chairman of the Joint Committee, Lord Carter's reference to the case of Jane Campbell and how an advance statement would have made a big difference in her life.

The MDA recommends that there should be a mechanism to record the existence of an advance refusal or statement and that there must certainly be an obligation on healthcare providers to ascertain whether an advance statement exists. However, an advance refusal or statement should not be invalid if not registered or lodged, although the benefits of recording the existence of an advance refusal or statement should be made clear to the donor.

4. ADVOCACY

The MDA was asked specifically to comment on the role of advocacy within the Bill and what our priorities should be in terms of funding for advocacy. We believe that a right to an independent advocate will provide critical safeguards in the Bill. Advocacy support will help people to have a say in their own lives and ensure that all practicable steps are undertaken to enable the individual to make decisions. We also think that advocacy will be important in ascertaining what is in the personal best interests of the service user. An advocate would also help to resolve areas of conflict or dispute that may arise between a person and a carer and may be a critical independent check on the general authority to act, particularly for major decisions, such as where someone lives or in considering a particular form of treatment. Its role, as a supporter and facilitator of decision-making, is distinct from that of a solicitor or legal adviser. Without advocacy support, the MDA is concerned that a person may be wrongly or inappropriately assessed as not been able to make a particular decision or not be able to participate in the decision-making process.

The MDA has recommended that the Government provide funding to ensure that every local authority area has an independent advocacy service to provide support for people affected by the Bill. We have prioritised two areas in terms of funding: First, advocacy is important when major life changing decisions are taken. It will be vital to ensure that the individual's needs are properly addressed and their preferences taken on board. We recommend that there should be a duty on health and social care professionals to involve an advocate when a key life changing decisions need to be taken or when disputes around these situations arise. Secondly, a right to an independent advocate where the individual has no one to consistently support them, for example if they do not have a formal or informal network of support. Where an individual is moved around and between services, the advocate may be the only person they have known for any length of time. In such situations, the advocate will be crucial role, providing both continuity and reassurance to the individual at the centre of the decision making process; and acting as a valuable source of information about that individual's behaviours and communication methods.

5. COURT OF PROTECTION AND DEPUTIES

The MDA made a number of recommendations on the role of deputies when we gave evidence to the Committee. In addition, we have concerns as to whether the court of protection will be accessible to people who have difficulty making decisions or have been assessed as lacking capacity. The accessibility of the Court, particularly in relation to single orders, will be particularly important if the Committee accepts the MDA's recommendation that certain decisions should be removed from the remit of the General Authority.

The MDA believes that when someone is making an application to the Court, or a deputy is being appointed there should be an automatic right for the person making that application to have access to legal advice and to receive legal aid. Resources will also need to be found to secure training for Court judges and other staff on the needs of the various client groups they will come into contact with.

MDA proposes an additional mechanism for challenging a decision taken under a general authority to act. We would like to see the jurisdiction of the new Court of Protection extended to include arbitration hearings before a district judge (equivalent to "small claims hearings" in the county court). This could help resolve disputes and prevent more formal applications to the Court of Protection. It would also clarify that formal hearings of the Court of Protection are to decide the most difficult cases and to appoint deputies to make difficult decisions.

6. MENTAL HEALTH BILL AND MENTAL CAPACITY LEGISLATION

The MDA believes that the introduction of new legislation on mental incapacity should precede the Mental Health Bill. This is because Mental Incapacity legislation sets out a legal framework of the rights and safeguards that apply to people who have difficulties making decisions. It also sets how people can make decisions for the future in case they lose capacity, through the appointment of a lasting power of attorney, or advance directives. Since both pieces of legislation are about how decisions can be made on someone else's behalf, it is crucial that they are consistent with each other. The Mental Incapacity Bill sets out the broader framework for decision-making on health and social care matters, and so it must act as the foundation for the Mental Health Bill, which only relates to the provision of compulsory treatment for mental disorder when certain defined circumstances are met. The Making Decisions Alliance would like to see a more "joined-up approach" to the proposed legislation of mental capacity and mental health.

Furthermore, the objective of the Mental Incapacity Bill is to maximise autonomy and respect and to provide support so that people are able to make their own decisions about their lives. This framework should therefore ensure better support and care and treatment for people with mental health problems and help prevent unnecessary and inappropriate use of the Mental Health Act.

Finally, there is greater urgency for a Mental Incapacity Bill. This is because it relates to day-to-day decisions, for which there is no existing statutory framework, whereas the Mental Health Bill is for the most difficult of cases and there is already existing legislation to deal with these cases.

Wednesday 8 October 2003

Members present:

Carter, L. (Chairman)	Mrs Angela Browning
Fookes, B.	Mr Paul Burstow
Knight of Collingtree, B.	Jim Dowd
McIntosh of Hudnall, B.	Stephen Hesford
Pearson of Rannoch, L.	Mrs Joan Humble
Rix, L.	Laura Moffatt

6. Memorandum from the British Medical Association (MIB 1185)

INTRODUCTION

1. The British Medical Association is a professional association of doctors, representing the interests of all doctors in the UK. The Association has in excess of 127,000 members (around 80% of UK practising doctors are members). The BMA is an independent trade union and a scientific and educational body.
2. The British Medical Association very much welcomes the publication of the Draft Mental Incapacity Bill and believes it to be a significant step forward in the care and treatment of incapacitated adults. The Association would, however, wish to draw attention to a number of issues, and these are set out below.
3. The BMA is grateful for the opportunity to submit evidence.

“BEST INTERESTS” OR “BENEFIT”

4. How “best interests” are interpreted in practice will be central to the success of the legislation. No attempt, however, is made to define “best interests” in the Bill. The equivalent Scottish Bill uses “benefit” instead of “best interests” and it would be useful to explore their respective advantages. It is possible, for example, that “best interests” might preclude any possibility of a treatment or intervention that does not harm, or risks only minimal harm, to the incapacitated person but that could provide a significant benefit to a third person. Presumably, any intervention that the individual would have clearly wished to occur would be considered to be in that person’s wider interests, even if not clinically beneficial. This might include, for example, genetic testing to benefit other members of the family. If this cannot easily and clearly be incorporated into the Bill, the BMA would like to see a separate clause introduced in the Bill that would enable, with appropriate safeguards, the possibility of interventions of this kind.

SCOPE OF POWER OF ATTORNEYS

5. According to the Bill, a lasting power of attorney (LPA) does not extend to the refusal of consent for withdrawing or withholding life prolonging medical treatment unless it is specifically mentioned in the LPA. The BMA is concerned that this might serve to create a presumption that unless it is specifically rejected in the LPA, patients would always want whatever treatment was available. The BMA is concerned that this implies that treatment is almost always in the best interests of the patient. The BMA considers, in contrast, that treatment should only be provided where it is likely to provide a net benefit to the patient. If this clause remains, it must be made clear that continuing invasive treatment should not be given when it is not in the patient’s interests, even if the attorney has not been authorised to refuse life-prolonging treatment.

SCOPE OF GENERAL AUTHORITY

6. The BMA has a number of concerns with the general authority. These are listed them below:
 - What are the limits of the general authority in relation to medical treatment? Are there thresholds of severity beyond which the general authority cannot extend, and if so, where do they lie?
 - Are there any limits to the general authority in terms of necessary as opposed to optional treatments?
 - How will conflicts between the LPA and the general authority be managed? Also, how will conflicts between individuals who both believe they are operating under the general authority be managed?
7. Clear guidance will therefore be needed in the Code of Practice as to the scope of the general authority, at what point a decision by a proxy or the Court is required, and whether the Bill applies to “necessary” as opposed to elective treatments, even though the elective treatments might benefit the patient.

DISPUTE RESOLUTION MECHANISMS

8. How will disputes between attorneys and health care workers and between separate individuals both of whom may believe they are operating under the general authority be managed? Although the Bill creates a provision for recourse to the Court of Protection for rulings on single issues, the BMA would like to see the Code of Practice containing detailed advice in relation to mechanisms for the local management of disputes about the best interests of the donor, particularly, for example, where the decisions are not of the gravity of withdrawing life-prolonging treatment but nevertheless raise best interests issues.

9. ADVANCE DECISIONS

- The BMA welcomes both the inclusion of advance refusals in the Bill, and the clarification, under section 25, of doctors' non-liability where they act in good faith in accordance with what they reasonably believe to be a valid advance directive, or where they act in contradiction to an advance directive that they did not know existed.
- The BMA would like to see mention in the code of practice that unless a woman's advance refusal specifically refers to refusal of life-prolonging treatment while pregnant, it is extremely unlikely that the refusal will be deemed to be valid.
- No mention is made of the relation between the Incapacity Bill and mental health legislation in regard to advance refusals. It is the BMA's understanding that, currently, advance refusals are not applicable to treatment provided under mental health legislation. The Association would not wish to see any change in this position.
- The Association would like to see mentioned in the Bill that an advance refusal or directive would not be valid if it was produced under coercion.
- The BMA is concerned that some existing advance directives may be deemed invalid if they do not meet the specific requirements of the Bill. The Association would not want the Bill to take away any existing common law mechanisms for making advance statements.
- The BMA considers that people should not be able to refuse, in advance, the provision of "basic care", which, in the Association's view, includes the administration of medicine, or the performance of any procedure which is solely or primarily designed to provide comfort to the incapacitated patient or alleviate that person's pain, symptoms or distress. The Association would like to see this in the legislation or the code of practice.

CODES OF PRACTICE

10. The Association would hope to be involved in any consultation process where the code or codes of practice will have an impact on the work of doctors or other health care workers.

OTHER ISSUES

Transplants

11. While the BMA considers that, as a matter of general principle only competent adults should be considered as live organ donors, and supports the view that proxies would not be able to consent to live donation, the Association would wish for scope to remain for truly exceptional cases to be considered by the courts on an individual basis.

Power to call for reports

12. The Bill refers to Lord Chancellor's Medical Visitors and the requirement for them to carry out medical examinations of individuals who may lack capacity, and who may also be required to inspect those individuals' medical records. What powers will these Visitors have where individuals do not consent either to examination, or to the release of their medical records? For example, where it is believed that an individual may lack capacity and a medical report is requested, will the Visitors be able to proceed in the face of a refusal from the individual concerned? If not, how will such a situation be managed? Is the post and role of Medical Visitor a new post or are Medical Visitors already employed by other statutory bodies?

Restrictions on the general authority—the use of force

13. While the BMA fully endorses restricting the use of force or other constraint to interventions solely directed at promoting the best interests of patients, there may be some unintended consequences of the Bill as drafted. Would leading or guiding an incapacitated person by applying slight directional pressure constitute a use of force and if so could it only be justified in order to avert a risk of serious harm? Bournemouth highlighted uncertainty about the issue of whether compliant incapacitated persons were in fact detained. What would actually constitute a statutorily significant restriction of liberty and would it always need a substantial threat of significant harm to justify it?

Witnesses: **Dr Michael Wilks**, Chairman, BMA Medical Ethics Committee and **Dr Vivienne Nathanson**, Director of Professional Affairs, British Medical Association, examined.

Q243 Chairman: I would like to start by thanking you for attending and for your written evidence, which has been very helpful. The session, as you realise, is open to the public and is being recorded for broadcasting and there will be a verbatim transcript which will be published with the report, and you will have a chance to check that for accuracy and return it quickly. There should be a note of the relevant interests of the Members of the Committee on the table. The representatives of the departmental team are present as observers. Even though we have microphones the acoustics in this room are not good, so if you could speak up that would be helpful. If we are unable to reach any questions we would be happy if you would write to us on those and, also, follow up any points which were made in the evidence which you might want to expand on the final point, which I make to all witnesses, is that we are not here to devise a White Paper on mental incapacity. We are here to comment on a draft Bill and, therefore, the questions are not structured round the structure of the Bill. If you would like to introduce yourselves.

Dr Wilks: My name is Dr Michael Wilks and I Chair the Medical Ethics Committee of the British Medical Association.

Dr Nathanson: I am Vivienne Nathanson. I work on the staff of the BMA where I am Director of Professional Activities, which includes responsibility for ethics, science, education and other professional matters.

Q244 Chairman: If I can start by saying that the draft Bill would put into statute a number of principles which are already encompassed by common law. It would also establish a number of new systems relating to substitute decision making. In your view does the draft Bill go far enough to clarify and improve the decision-making process for professionals, families and carers of those who are currently unable to make decisions for themselves?

Dr Wilks: Thank you. Generally speaking we certainly think that it does. I think the overriding point for us as a starting point is that there is a significant vacuum in the middle at the moment in the decision-making process in health care. Obviously that is reflected in other areas of difficulty for incapacitated people in making decisions for themselves about other issues, but from the British Medical Association's perspective it is in health care decision-making that we have a particular interest. The problem is that in terms of deciding what is either of benefit of best interest in a particular case, where a patient is incapacitated it has to be done by reference to family members but, ultimately, the clinical decision is with the doctors, so there is a process of clinical assessment followed by some kind of discussion with family members as to what is in the patient's best interest in order to benefit the patient. As I said, that has been a vacuum and it is, therefore, extremely good, in our view, for patients that this kind of framework will now exist, and particularly it is good for doctors as well because we are left with a decision-making process in which

there has been some uncertainty, and to have a process in which people make statements about themselves either verbally to the family and have discussions with family and, maybe, even write advance statements or advance refusals so that everybody is thinking a bit about the type of health care decisions they would like made on their behalf when they become incapacitated can only be good for the process of health care decision-making. So we do welcome and have pressed for some time for this type of legislation.

Q245 Chairman: You mentioned the uncertainties that you have in a particular situation. What would those be?

Dr Wilks: Obviously there are two stages in dealing with any patient with an incapacity. The first is to make a clinical assessment and arrive at a judgment as to what will be clinically in the best interests of the patient. However, medicine has moved very rapidly towards the idea that whether we talk about benefit or whether we talk about best interests, we talk about something that is from the patient's perspective. Just because a doctor thinks something is of clinical benefit does not mean that it is in the best interests of the patient from their perspective. So the difficulty is that when someone is incapacitated you simply cannot talk to that patient. You may be able to get some idea of some decisions that their level of capacity will allow them to make but in health care terms these are often very difficult decisions and the only way to reach a best interest judgment is to go through the people closest to the patient. So because this Bill also makes it clear that advance statements of general wishes and, particularly, advance refusals of treatment on the face of the Bill are things that we would like to encourage patients at least to think about, there is far more information available to the doctor at the time as to what that patient would wish as opposed to what the family or simply the doctors think the patient would wish. That is very helpful.

Q246 Mrs Browning: I wonder, Dr Wilks, if I could just ask you to reconsider the order in which you suggested this process should follow? I think you told us "clinical assessment followed by family members". I can think of examples where actually doctors would be better informed of the clinical assessment if they consulted with family members first. Let me give you two examples: if you are dealing with somebody who has an autistic spectrum disorder they could have quite a variation in behaviour and communication problems and it would actually help a doctor making an assessment if they got a few pointers from the family or named carer first in order to know how to approach that person and how to phrase questions—what sort of behaviour to expect at the assessment. So could I ask you to consider reversing that? Finally, Chairman, on quite a different issue in terms of the possibility or ability to communicate, my own mother is in hospital at the moment, at 86 with Parkinson's, having suffered a fractured femur and just about

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everybody who has looked at her has assumed that because she has no upper body strength because of the Parkinson's that she cannot walk, and that is now informing the way in which they are going about rehabilitation. They clearly have not asked her, and she has not volunteered the information, but she could walk before she went into hospital with the fracture. Had they asked a member of the family before they started rehab it would actually have informed the rehabilitation process. So, again, it is a question of the order in which that process is carried out.

Dr Wilks: Yes. Let us deal with the last point first, Mrs Browning. One of the things that we are very concerned about and support very, very strongly—and one of the concepts of the Bill—is this presumption that people can make decisions for themselves; somebody has to demonstrate that they cannot before they are regarded as lacking the capacity. It is also, as a subset of that, very important to recognise that people can make some decisions about some things, depending on their level of capacity, and not necessarily about other serious matters. So we are very keen that doctors and health care professionals should find ways to communicate with people to get their wishes out on the table so that we actually know the pathogenologies they have. Often that process of communication can be quite complex because the problems of the medical condition may make it difficult for them to speak. We have technology and all sorts of ways of doing that. On your first point, I did not sort of put a hierarchy of decision making as absolute. Many, many patients in these situations will be dealt with in a continuity of care scenario where doctors know them very well, nurses know well and the GP and family know them very well. However, where some kind of new medical problem arises in someone with a level of incapacity it makes it difficult for them to make decisions for themselves. The first job of the doctor is to be a doctor and make a clinical judgment as to what might be best, but that is only a first step; it is the wishes of the patient, as far as they can be ascertained, that decides what will then happen.

Dr Nathanson: If I can just add to that, we would always say, on the education side, and it is very strongly made, that the process of coming to that diagnosis is a process of talking to the patient and anyone else who has information which helps you about what the patient perceives to be the problem, because that is where you should be starting. There is no point in a doctor making a diagnosis of something, however interesting it is, if it is actually irrelevant to what the patient presented with and what the patient believes they need treatment for. That is the first thing that you are trying to work out. Sometimes the two things relate, but not always.

Chairman: I would like to move on to an area where we would appreciate your advice, which is in the area of medical research, which is not in the Bill.

Q247 Jim Dowd: The Scottish equivalent, the Scottish Act, does contain specific reference to research. This draft, at the moment, does not. Who has got that right?

Dr Nathanson: I think this is an extremely difficult one, but we would see it as almost denying patients the possibility of a real benefit if they do not have the possibility of participating in research. That then has to be extremely carefully constructed in a way that ensures that there is no possibility that individuals can be victimised or experimented on or exploited in any way, but providing one tries to build a structure to avoid that, and I think it is possible to make such a structure, then I think there are real benefits. There are simple benefits in research. The very process of being the subject of research often brings extra attention, so somebody who, perhaps, is in a long-stay facility may get considerable extra attention and sometimes the very fact of that attention can either make a medical difference or just make a social difference to that individual. Of course, there are the key issues that if you are going to look at some of the conditions that lead to people being incapacitated, the question is whether you will be able to really make leaps forward if you are not able to involve people with those medical conditions in the research. So we would believe that it should be in the Bill and we would encourage you to look at that.

Q248 Jim Dowd: I noticed you nodding enthusiastically.

Dr Wilks: Yes, absolutely.

Q249 Jim Dowd: How do you guard against possible exploitation or abuse of people with things such as Alzheimer's?

Dr Nathanson: I think you have to build up a process. We would see the process as probably being based upon research ethics committees looking at protocols, fully understanding (I think our research ethics committee process is getting better in the UK) that one part of their remit is to make sure that individuals who cannot necessarily talk for themselves or express their concerns—that it is their benefit and it is protecting them from exploitation that is being looked at. That is a key element of looking at a research protocol. Clearly, that also would mean that, for example, one would expect there to be limits on the kinds of potential risk for the procedures that you might put people through. One can foresee, for example, trying new medication—where there has been considerable research already on that medication—trying new treatment methodologies of different sorts, physical therapies of different sorts and so on, may well be things that can be tried because there is a reasonable body of knowledge of the effect on people without that condition and because the risk to the individual is properly limited. Those are the kinds of things which medical ethics committees would allow. We believe very strongly that research ethics committees should have this and the right to review to make sure, as research is going on, that they are able to go and say “Well, is it carried out according to the remit that was in the protocol?”

Q250 Baroness McIntosh of Hudnall: Can I ask a supplementary in relation to that particular issue? What happens now? How is research that relates to

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the treatment of individuals who suffer from incapacity conducted now? In what way would you expect the research environment to improve if the legislation that is being contemplated now included research specifically?

Dr Nathanson: I think research in these circumstances will be carried out in very much the way that we would perceive that it should be under the new legislation but with the caveat that I think there are grave doubts as to whether in fact it is legitimate always to carry out that research. There is quite a lot of limitation on research that is carried out on people who are incapacitated because people are unclear whether anyone can give consent to their involvement in research, but nevertheless a small amount of research does get carried out with very careful review by research ethics committees. What I think this would give is clarity about the fact that somebody can give agreement to research on incapacitated people. It would give the ability for people to say "This is the research we want to do" to be clear about what the rules were, what the limits were around it, and I think it would actually stimulate research in an area of medicine which is probably significantly under-invested in research terms, considering the numbers of people who are in some of the groups who are incapacitated and who may not get, therefore, all the benefits.

Q251 Baroness McIntosh of Hudnall: Are you saying, just to be clear, that some part of that problem of under-investment relates to people's insecurity about whether the research is legitimate in the first place?

Dr Nathanson: Absolutely.

Q252 Jim Dowd: Is the current structure of ethics committees strong enough, given the fact that this is essentially professionals deciding what is good for the rest of us, to secure the difference between seeking research and information which might be of great benefit to others further down the line and protecting the interests of the individual as a patient who still needs treatment and has not necessarily agreed to be researched upon?

Dr Nathanson: Over the last 20 years there has been a very significant and increasing investment in recruiting people to research ethics committee and training. I think what is very encouraging is that most of those are not just doctors, nurses and health care professionals; they involve members of the local community. I think many of them started off with hospital chaplaincy, for example, coming on board and other local members of public. That is a very important element because, in a sense, it gives all of us confidence that it is not just a desire to discover new science, it is actually about trying to weigh up and balance the benefits to individuals. I think, as well, having met a number of these people and having spent quite a lot of time talking to them about research ethics frameworks and guidelines, such as the declaration of Helsinki, there is really a pretty substantial body of knowledge out there that the requirement that they fulfil is to have at the centre of their considerations the safety of the

individuals taking part in the research; that they are meant to be and encouraged to be critical in all the right senses—critical in nit-picking at times if necessary—but also to have a mixture of both broad overview of how research fits in with the way in which patients are treated within hospital and their movement within the medical and other allied services but, also, how it fits into the way in which we, as the public, in a different sense, see the role of research. I am very encouraged by the sort of people I meet who are on research ethics committees and their huge commitment to actually serving the public good and helping researchers to shape the research in such a way that it not only gets the medical side right but it does that in a context of keeping the right protections for individual patients and actually gets the answers that we all need, as the public and the health service.

Q253 Jim Dowd: You speak, almost, of organic development, responsiveness and sensitivity of ethics committees. That would be very difficult to write into legislation, would it not? You would need to just rely on your good intentions.

Dr Nathanson: Yes, but there is now a research governance framework which I think is sufficiently robust to be reflected in legislation, and we do have a national framework—we have CORAC in England and Wales and the equivalent in Scotland—which is pretty robust and pretty well described in ways that means that you could write them into legislation.

Q254 Jim Dowd: Finally, is there a need for a formal substitute decision-making procedure whenever an incapacitated person needs to be involved in research?

Dr Nathanson: I think that the research ethics committees at their best would act as the substitute decision-maker on behalf of the individual patient. The difficulty with saying that otherwise it has to be some separate system is that I think you then start to, in fact, in a sense, almost diminish the ability to look at something protecting the individual patient, because looking at research is quite a complex business of balancing benefits and risks. So I think the research ethics committees are the best substitute decision-makers on behalf of the individual patient. Also, of course, you should also write into your protocols that anyone who has ever said "Under no circumstances would I take part in any research"—of course you would always honour that.

Q255 Jim Dowd: So your answer is, essentially, no, if we get the rest of it right that would not be necessary.

Dr Nathanson: Yes.

Q256 Mrs Humble: The issue that actually underpins the whole of the legislation is the assessment of capacity. As I am sure you are aware, the draft Bill does not actually make any specific reference to the processes of assessment, so my question to you is should the Bill specify how or by whom an assessment of capacity should be made, especially in respect of individuals who do not

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consent to be assessed? Should this be on the face of the Bill itself or should it be left to the Code of Practice?

Dr Wilks: I think, on balance, it is best that it should be in the Code of Practice. You may be aware of guidelines issued by the British Medical Association and the Royal Society on the assessment of capacity. We have a second edition of that due for publication in March next year. Were you to find that a useful guide to the actual process I think that we would welcome reference to that in the Code of Practice. I think that would be a better thing to do than put it on the face of the Bill. On the specific point about the refusal to be assessed, obviously that creates a dilemma. The guidance does go into that and makes it clear that it is possible in the absence of consent to make some kind of assessment of capacity, although obviously that is not as complete as if you had the co-operation of the patient. It may be adequate to make some judgment about someone's level of capacity and to move on to make some decision about how that should be managed. The problem is that in the absence of consent you cannot really document and pass on information except under exceptional circumstances. So we do deal with that, but I think that it is possible sensitively, in most patients' cases, even in the initial presence of refusal, to work through that and to get an assessment done.

Q257 Mrs Humble: Could you clarify for the benefit of the Committee who in your Code of Practice does this assessment? Is it a clinical Code of Practice? Is it doctors who do the assessment? As I am sure you are aware, there has been some discussion about whether lawyers should be involved and whether it should be a legal assessment or a medical assessment.

Dr Wilks: Obviously our terms of reference are relevant to health care and the capacity to give consent to health care, but we have written this guidance jointly with the Law Society and there will be many circumstances where lawyers will take a view on the capacity of people to make decisions about their financial affairs or their housing affairs but not necessarily relating to medical treatment and may not require a medical type of assessment in order for other professionals dealing with people's affairs to feel they need that medical input, but we would obviously say that where important health care decisions need to be made you have to go through a very careful medical assessment because there are so many different types of mental incapacity which fluctuate and vary and, as I said, they will vary according to the level of decision-making that is being required.

Dr Nathanson: Just to reinforce that, in a sense what we are really saying is that the person who should be assessing is the person who understands what the decision is that has to be made, because they understand the complexity of the decision. So, as Michael said, if it is about financial affairs or legal affairs it seems that it would not be a doctor, who may have no understanding of the complexity of that decision. So it is somebody who can understand what that decision means for that individual, again,

based upon the fact that we should always assume that people are capable until proven otherwise, as it were.

Q258 Stephen Hesford: Dr Wilks, earlier you stressed the primacy of the idea of a presumption against total incapacity. At the moment that is in Clause 3. Would you like to see that primacy put, say, in Clause 1 or somewhere stated more obviously?

Dr Wilks: I think that what we would certainly like to be stressed is that primacy. There has been some question about whether there should be some sort of statement of principle at the beginning of the Bill or not, and certainly we think the Scottish legislation benefits from having that statement of principle. We have not encountered any difficulty with our colleagues in Scotland with the fact that that creates any kind of block or in any way restrains the clauses that follow the statement of principle. Yes, I do think that the presumption that somebody is capable of making decisions until you can prove otherwise is so important because, as Mrs Browning asked earlier, so many people around someone with incapacity make assumptions that incapacity equals total incapacity. We want to stress the point that many people can make a lot of decisions about themselves without any help from doctors and relatives, and that should be respected.

Q259 Chairman: Can you envisage a situation where somebody has the capacity to reach a decision but it is a fluctuating capacity, such as in dementia, and when you come to implement that decision they have a complete reversal of that decision and say "We do not want to do this, it is all wrong"? What do you do in that circumstance?

Dr Wilks: I think the answer would be in two parts, Chairman. The first is to have more information from that person when they have capacity and when they are competent to express general opinions. That is why although there may be difficulties around advance statements, whether general or specific, in terms of refusal, they are to be welcomed as expressions of wishes by people who have thought it through, and talked to their families at times when they have full capacity about how they would wish to be treated or, perhaps, not treated when they lose their capacity. Obviously at the time when someone has got a fluctuating capacity that will depend very much on the clinical reason for that and how treatable that was, and building up the experience of how that person was expressing their wishes at times when they were rather more lucid. Obviously, people with fluctuating capacity may have to recognise as having some times when they cannot make a proper assessment for their own best interests and that at those times proxy decision making will be made on their behalf.

Dr Nathanson: Just to add to that, the fact is that in medical decision-making patients with what you might call full capacity change their minds from time to time and it is one of the things that we have to recognise. Perhaps the key thing for the clinician then is to try and talk through with the patient what

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it is that is making them express what is obviously concern—if you are not certain whether you want a particular treatment or not—and to try and get to the bottom of what it is: what the patient's fears and expectations and hopes are. It is exactly the same with somebody with fluctuating capacity, although you have got that extra dimension; it is to really find out what is underneath that because the complication of a fluctuating capacity is you may not be sure at which point in the decision cycle somebody is capable of making a decision. So it is very important that doctors are aware of the need to avoid only agreeing with a patient's decision when it agrees with what the doctor would like the patient to say.

Q260 Lord Rix: Going on to advance decisions, if they are going to appear at all in the Bill should they be on the face of the Bill and should it stipulate that they be in writing? Should it stipulate that the family must be consulted before the decisions are written down and should they be witnessed by a competent professional—somebody who knows you, such as your family doctor or your lawyer? Also, as a supplementary to that, how would you deal with advance decisions—living wills—which are currently being held by many lawyers up and down the country? My wife, for instance, has left advance decisions. How would you deal with those on the face of the Bill?

Dr Wilks: Quite a few questions there. I think, first of all, it is very important to distinguish between a general advance statement of wishes and the advance refusal. Common law respects and requires doctors to respect a competent refusal of treatment, and you may be aware of cases where doctors have come unstuck by not doing that. Therefore, we welcome the inclusion of advance refusals of treatment on the face of the Bill because it underpins common law requirements already. I think the situation is much more difficult when it comes to more general statements of wishes. It is very hard for us to see how one could reflect the status of a rather flexible process of documentation of expression of wishes—a generalised expression of wishes—on the face of the Bill. Secondly, because they may well reflect a person's wish to be treated by a doctor in a certain way, without sounding defensive about it, it is very difficult for a doctor to be held to give a certain treatment that has to be given at the time when the judgment is made as to what is in the patient's best clinical and other interests. So we have some difficulty with a more general statement being included on the face of the Bill. We do not think that it should be a specific requirement that the advance statement should be in writing. Therefore, if it is not in writing it may be secondary whether it should be witnessed because many of these processes and discussions will be taking place at a time when the person is already hospitalised or in long-term care under the GP or under hospital or community care. Although there may be some written statement from before, what we see is a process of information; consent is a very dynamic and fluid process in which health care professionals get some idea from the

patient as they go along treating the condition as to what those wishes might be. That is in the mind of the health care professionals as well as, hopefully, the notes as well. So I think to require a restrictive statement as being the only evidence of a person's wishes and not to rely on other more generalised statements to doctors and what is put on the notes is probably not giving that patient the best opportunity to have all the balances and checks pass through their thinking. We are very concerned, obviously, that if you make an advance statement or advance refusal of treatment you do not just stick it in a drawer and forget about it; people have to know it exists and doctors have to know it exists or family have to know it exists, and we certainly are very supportive of the idea that the importance of that document should be strengthened by there being an offence to conceal or destroy it, as I think is on the face of the Bill.

Q261 Mr Burstow: I really wanted to pick up on this issue of assessment of capacity and the ideal position being one where you can have a conversation with a person when they are more capable of understanding the decision they are being invited to take. Evidence from, I think, the Audit Commission and, also, from the Alzheimer Society does give some cause for concern about diagnosis, in respect of dementia, being quite late in terms of it being reported to carers and family members and then to the individual. Do you think in any way enacting this legislation might lead to a change in practice in terms of an early diagnosis so as to facilitate that sort of discussion?

Dr Nathanson: It is difficult to know whether it will lead to earlier diagnosis. I think there are many things going on that lead to late diagnosis of dementia, including the fact that it is a devastating diagnosis because there is no effective treatment in most circumstances. It is one which doctors, in that sense, are reluctant to make because of the effect it can have on that individual and their ability to live independently—not necessarily their physical ability but just their ability in the sense that people tend to move in and say “You are no longer able to make decisions” because of the diagnosis. It is also, of course, a diagnosis of exclusion very often, so people are always for searching for things that are other causes of whatever the state is, so that hopefully some of it is treated. What the legislation will do, and one of the reasons—just picking up Michael's previous answer—why we are so enthusiastic about this, is that there will be far more discussion, we hope, within families, between individuals and their doctors and other health care workers and individuals and other people who help them in other areas of their life about “What I would want if I cannot make decisions for myself, both medical and other”. I think that might have a significant impact in terms of the willingness to make this devastating diagnosis because patients will already have expressed some of the views about the things that they would want to happen to them, whether it is what happens to the family home and those sorts of things, which GPs, in particular, are very aware of

being an important issue for many people in these circumstances. So I think that it might encourage it. I think it would also lead to a situation where the family felt more confident of saying "A system is in place to help us make decisions" for whoever it is who may have dementia, and I think that is to be welcomed. Again, the earlier the diagnosis is made, although there is not currently any treatment, does mean the possibility of research and the possibility of new treatments as they come along—and who knows what may happen? Sometimes we are surprised by the speed with which something comes in that can treat so-called untreatable conditions.

Q262 Stephen Hesford: Just to come back to your answer on advance directives. What struck me was when is an advance directive not an advance directive and when is it just simply a contemporary conversation that you are having with a patient? I broke my leg and went into casualty, then I went on to a ward and they asked me did I want a pin or did I want plaster? That was not going to be done immediately. So I agreed with them what I was going to do. Was that an advance directive or a contemporaneous decision? If it is a contemporaneous decision, is that not of a different quality to the issue that we are really grappling with as to what an advance directive should be properly able to do?

Dr Nathanson: I think an advance directive is clearly something which says "In the future if I cannot make a decision" in its traditional sense. A contemporaneous decision is the treatment now or in the near future. I think where we find the soft area in between is that from the conversations you have perhaps, particularly, with your GP, your GP will learn something about the things that are of importance to you, the factors that you bring into play when you make medical decisions. All of us have slightly different values in those terms. For example, I always say to my dentist when I go there "There is only one key factor, as far as I am concerned in dental decision-making, which is get me pain-free as soon as possible". That is important and he knows that. So, in that sense, that is a bit of an advance directive; if I could not make the decision he knows what is the most overriding issue for me. In the same way that is where we find not necessarily specific advance directives which have a lot of detail in them, but the discussions which take place are part of this slightly softer system of giving information to people who, if they have not made a formal advance directive, at least have some more idea of the things that matter to you. Part of that will include who it is in the family, perhaps, who makes decisions on your behalf. It is very important often for an elderly person on their own that the doctor knows which of the family members is most in touch with the way they live their life and things that are important to them. In that sense, that is where you get into this soft area, and we would move towards the advance directive having a mixture of things; there is the element of continuing discussion with the GP from time to time, with some recording of that, so that the GP has a trigger and knows there are

things that matter to you which will help. It will help while you can make decisions for yourself as well but it will help the GP to know how to present things to you because they know what are the issues in your decision-making process.

Dr Wilks: We have talked about communication a couple of times, and I think that one of the areas that we see as perhaps a weakness at the moment in health care, and one which I think this Bill will help to promote an answer to, is that while, of course, incapacity is not necessarily age-related we are talking primarily about older patients. Many older patients enter hospital with a lot of difficulty about communicating what they want in the way of their general treatment to doctors. I think, to be fair, some doctors have difficulty engaging in that kind of discussion because very often they will be talking about issues in relation to decision-making that they are uncomfortable to intrude upon. So the fact that doctors will need to have more understanding about patients' wishes because of the incapacity legislation, I think, will make it more important that we, as doctors, engage in those sorts of conversations with a bit more readiness and willingness. I hope it will have a cumulative effect.

Q263 Mrs Humble: If I can just go back to your answers to Lord Rix's questions about whether or not the advance directives should be written down, if they are written down and there is a possibility of having a register and then you, the clinician, could access that register just to know that somebody had made some advance directives about their future care and then you could raise it with them—but then you went on to talk about the fact that advance statements can be part of a conversation that Stephen has been talking about. How would you then know? If that conversation had been with a GP you would not know about that.

Dr Wilks: Not necessarily.

Q264 Mrs Humble: It depends. It may well be that GPs write them down, but unless you have access to detailed records from the GP and can trawl through them, and it may go on for several months even years, you are not going to know. So if it is not written down how will you know, when somebody arrives in hospital and you are having to deal with them, that they have actually made those sorts of statements about their future treatment?

Dr Wilks: Very often in the acute situation that may not be possible. In an acute situation doctors will act in the best interests and do what is best. I think in a more long-term, chronic situation there is time to get that kind of information from the GP and, also, from any written record. Obviously the presence of their written statement is very helpful, but I think there are two different scenarios of advance statements that we need to keep in mind. The first is that even something as tight as an advance refusal of treatment must be relevant to the situation the patient is in. One of the difficulties about making an advance refusal of treatment is that you, first of all, as a patient have got to visualise the circumstances you are going to be in in which you might not wish

to have treatment. Secondly, of course, medical technology might over time produce a much greater potential benefit in treating your condition than was clear at the time you made the advance statement, which is why we need to have a dynamic review and a further discussion with the patient. The other scenario would be where the advance statement simply tied the doctor's hands too much, and at the time the patient is having a more rational conversation with other family members further down the line, again, that sort of information about a balance of views needs to be brought in. That is one of the reasons why we go back to the point that a clear advance refusal of treatment is something that common law recognises and which, I think, wisely should be on the face of the Bill. It is much more difficult to see how one addresses the problem of a more general statement of wishes. While obviously doctors would wish to give that treatment which patients would wish to have, they need to consider the clinical benefits and harms at that time. So, yes, helpful to have something in writing, and we would certainly welcome that, but we would also welcome other evidence to help us build up a picture.

Q265 Laura Moffatt: I wonder if we could just pursue this point—it is quite a difficult area—of advance decisions. The BMA have already stated that they would find it very difficult if a patient their doctor was caring for refused basic care—that they would find that extremely difficult to adhere to. Certainly as a nurse of 25 years in the NHS it is something that is absolutely a bar to me. That would be about making sure that somebody is clean and comfortable, with a moist mouth. There may be some difference of opinion over being pain-free. What circumstances, firstly, could you see where that would be appropriate and why do you believe that for basic care, if there is a refusal, it should not be taken any notice of?

Dr Wilks: In terms of not taking any notice of an advance refusal of treatment, going back to what I said a little bit earlier, the doctors need to be absolutely clear that it is valid. Does it refer to the situation the patient visualised? If there is any doubt about that the doctor has an obligation to at least review that and say “Well, here is a situation the patient did not envisage”. It is either going to be some kind of change in treatment because the advance refusal is quite old and things have moved on, or it could be that a completely unanticipated medical emergency has arisen which is highly treatable, and the doctor can say that is a good idea. Obviously, we do not want to support the idea of competent statements of refusal of treatment and then undermine that by saying “Well, we will not take any notice of it”. It would have to be an exceptional circumstance in which we genuinely felt that the person had not anticipated that precise situation. As far as basic care is concerned, we are talking here about basic care; we are talking about the offer of fluids, warmth, comfort, pain relief. I think if we are talking about rights of patients, we are, to some extent, talking about the rights of health care professionals, and they need to be able to treat

that kind of level of need. If that refusal in advance has been made to those who care, we think that it would be very, very difficult for doctors to respect that, partly for other health reasons in terms of other people and partly because doctors and nurses simply cannot leave somebody without those basic functions. We would regard that as an unacceptable binding of doctors' freedom to act in someone's best interests, while entirely accepting that refusals of treatment, even to the extent of lack of support of treatment, are covered by common law and should be protected.

Q266 Laura Moffatt: So you are very clear you would like to see stated in the Bill that basic care should never be able to be refused?

Dr Wilks: We think yes, in advance.

Dr Nathanson: In advance.

Q267 Chairman: If it were in the Bill this would require some kind of definition of basic care.

Dr Wilks: We can refer you to a number of definitions. The definition of basic care in the document we produced on advance statements about medical treatments is quite helpful, as also is the one on the withdrawing and withholding of life support treatment.

Q268 Mrs Browning: On that point about the definition that would be there, and I can understand why you want to see it, have you thought through what might be the outcome if you as doctors faced legal challenges either from, say, the relatives in terms of what was done at the time and in respect of the difference between, say, basic care and some other form of interventional treatment? Presumably it is on a scale; it is not either or. Also, whether you would be open to, for example, lobby groups taking test cases through courts in order to define that for the particular group that they represent?

Dr Wilks: Yes, I agree that there could be some fuzziness around the edges but we would hope that in the vast majority of cases it would be quite clear that a doctor or nurse or health care professional acting in that way of providing basic care would be doing so for the immediate comfort of that patient and not to in any way alter the course of disease.

Q269 Jim Dowd: Notwithstanding the heated dispute between basic care and treatment, Stephen mentioned earlier the provision in Clause 3, the presumption against a lack of capacity. Are you hedging towards inclusion somewhere in the Bill of a parallel presumption against lack of treatment?

Dr Wilks: I do not quite follow the point.

Q270 Jim Dowd: The presumption in Clause 3 is that unless it is demonstrable that people have incapacity you assume they do not. Therefore, in the circumstances particularly that you describe as unforeseen or perhaps unforeseeable circumstances that people might find themselves in, notwithstanding the existence of an advance directive or instruction, should the presumption be that they should be?

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Dr Wilks: No.

Dr Nathanson: We believe it is absolutely imperative that there is no assumption or presumption that people should or would say yes to treatment or no to treatment, that it should be absolutely open to an individual, beyond basic care, to make those decisions for themselves with the support, help and advice and all the other things that the health care professional and, indeed, the family, friends and others are around to provide, but that there should be no assumption or presumption of accepting treatment.

Q271 Jim Dowd: Even if they were comatose, for example?

Dr Nathanson: That depends upon the circumstances in the sense that when somebody presents at the hospital, for example, with nothing known in advance, as an emergency, then we make the assumption that you will do what you can to help that individual, particularly if there is not time to consider what their wishes would have been. But that as soon as possible you then find out what their wishes are, if they are known, or would have been, and that gets factored into the longer term, which is actually quite short-term in terms of decision making. You do not wait when somebody collapses and stops breathing to find out whether they want to be resuscitated; you do that at the time unless in advance, if they are already on a hospital ward and they stop breathing, in which case you do know what their wishes are and those wishes can be respected in those circumstances.

Q272 Jim Dowd: So the actual presumption is towards treatment, is it not?

Dr Nathanson: In an emergency when nothing is known, yes.

Dr Wilks: That, of course, in some cases has a strong evidence-based dimension to it. You may well be faced with a situation where somebody says "There are circumstances in which I do not wish to be treated" but we do know, for instance, that if somebody has a cerebral vascular episode, a stroke, the better the acute treatment is as quickly as possible the better the chances of a good outcome. So I think it is a requirement for a doctor to act in the patient's best interests by providing treatment at that stage.

Q273 Baroness McIntosh of Hudnall: I think the term "best interests" has come up again and again and again in this discussion, as inevitably it will. It is an interestingly volatile idea, best interests. It is in this Bill, it is not in the Scottish Bill; the Scottish Act talks about these issues in another way. Could you tell us whether you think that it would be in the interests of making a better Bill for "best interests" to be defined more narrowly or more precisely than it currently is, and specifically, can you also talk to us a bit about how clinical best interests are to be balanced against best interests taken to be in a wider sense? I noted in your written evidence that you did mention the fact that you felt that best interests could be taken to include a wider set of interests than

just the patient's own immediate clinical interests. The other question we wanted to ask was whether the Bill would benefit from a statement of principle similar to that which is incorporated in the Scottish Act being on the face of the Bill?

Dr Wilks: Yes, I think I have alluded to this point already. I think we would, because experience in Scotland has suggested that it is helpful and certainly does not create any circumstances in which the clauses that follow the statement of principle in any way are restricted or curtailed. So, yes, we would like to see that. We would also like to see a definition of "best interests" if one can be found, because you quite rightly said it is a complex area. We do not have a particular view as to the benefits of having either benefit or best interests as your terminology, but there are some differences. What is clinically and generally beneficial to somebody is perhaps a little bit clearer than entering into a competitive thing about which best interest is best. I do not think that is a huge issue. What I do think is that we need to be absolutely clear, as the BMA has consistently said, that the doctors role is two-fold: a clinical, best interest assessment must be made of what would be the best treatment; what would be the advantage of treating or not treating, and you can make that assessment in not narrow but very defined terms of physiological outcome but you may well not be acting in the patient's overall best interests in that that is exactly not what the patient wants you to do. It is also quite possible to achieve greater clinical benefit in terms of measurements of blood levels of things and regard yourself as doing an extremely good clinical job and not noticing that the patient is suffering terribly from their condition even though you may manage to maintain the blood sugar. A good physiological outcome is by no means not the only goal of good medical treatment. We define best interests first of all in much wider terms and secondly we define it in terms of what the patient himself or herself would regard as a benefit or best interest to him or her, not what the doctor thinks. That is where we have this vacuum, which I have already alluded to, where the opinion, the view of witnesses and close family members is helpful to the doctor in making a decision. What the draft legislation does now is to codify that to somebody who has a responsibility to look after those best interests.

Q274 Baroness McIntosh of Hudnall: Can I follow that up? One particular aspect that slightly concerns me is that you appear to be suggesting, certainly in your written evidence, and you have alluded to it elsewhere today, that there might be circumstances in which something which was not in the direct interest of the patient, but might be in that patient's wider interest, for instance, an intervention was going to be of benefit to his or her family, might be construed as being in the patient's own best interest. I am sorry that is a very complicated sentence but it is a rather complication thought. I am concerned about the possibility that you are moving the idea of best interest slightly away from the patient's own interest and towards the interest of others connected to the patient rather.

Dr Wilks: I think that depends how widely you cast the definition. This is an issue that needs to be addressed and thought through and not ignored because the best interests of someone who has a genetically linked disease which has been diagnosed which cannot be treated therefore a genetic test which would be of no benefit clinically or otherwise to them but it might nevertheless be to the benefit of them as a family member in helping to diagnose the possibility of medical diseases in their immediate family and intervene on those and possibly treat them or alleviate their progress. I think there are circumstances where genetic testing is a good example. The test about the test is that it causes minimal harm to the patient but then benefits somebody else is not something that we should prevent the opportunity to do.

Q275 Baroness McIntosh of Hudnall: It seems to me this does link very closely to the research issue.

Dr Wilks: I think it is an important area that needs to be explored rather than ignored.

Chairman: I am anxious to get your view before we finish on general authority.

Q276 Baroness Knight of Collingtree: In fact my question follows on very well on what has just been said because I want to ask you about your concerns which you expressed on Clause 10(4)(b). When you finished your comments about the lasting power of attorney you said, "the BMA considers that treatment should only be provided where it is likely to provide a net benefit to the patient". It seems to me that that is very straightforward, that is what you believe, but it does not quite tie in with what you said about best interest, and that worries me. Can you define for this Committee what you mean by "net benefit", is it getting better or is it staying alive or is it avoiding suffering? What is it?

Dr Wilks: You make two judgments on that. As I have already said the assessment of a patient's clinical situation may lead you as a doctor to feel there are certain treatments that are appropriate or not appropriate or there may be no treatment that is appropriate and the treatment might be withdrawn. A fundamental principle of good medical practice is that if a treatment is no longer providing benefit to a patient, and therefore by definition they will be causing harm, then the doctor has an obligation at the very least to consider whether it should be withheld or withdrawn. That is a very clinical type of assessment. As I said before the best interests of that particular patient can only be judged in the light of how they would feel about circumstances in which they might or might not wish to have treatment or might refuse treatment or have treatment withdrawn. We are very concerned. As I have said there is absolutely clear guidance, both our guidance and more importantly in the General Medical Council's guidance, there is a process of consultation and consensus taken with families even though it is the doctor that makes the clinical decision under the current rules, it is absolutely essential. What we are welcoming here is the opportunity for a third party who knows the patient

well and acts within authority, probably an LPA, who can make decisions about treatment and can make decisions to refuse treatment. We believe that the overall guidance that both we and the GMC have produced about the withholding or withdrawing of life supporting treatment places a very, very strong requirement on doctors to behave in a way that is legal and ethical and compassionate. That is one of the reasons that we feel that a requirement for a patient to specify in particular that an LPA can only apply to the removal of life supporting treatment, it specifies that. We think it is unnecessary because of the large framework of very detailed guidance that we have. A final point on that is that we feel in the vacuum that that lack of authority might produce we are concerned that doctors may continue to treat simply because they do not have any directions not to and that treatment continuing in the circumstances where to continue treatment is futile would not be in the interests of the patient either. In brief what we feel is that people are competent to make decisions about all aspects of their health care, including views about life support treatment and they should be entitled to do so as long as at the time they understood exactly the implications of their decision.

Q277 Baroness Knight of Collingtree: I shall have to read those very lengthy remarks with extreme care before I judge whether my question has been answered or not. I did not understand one thing you said, you said that if no benefit was being experienced then there was obvious harm. I do not agree with that at all. I think a lot of people who are concerned about this Bill would also find it difficult to agree with you because having no benefit may be very sad but it does not mean that it is doing you harm exactly. I wonder whether it is possible that either yourself or Dr Nathanson might have read an account in the paper yesterday of an elderly widow who against her will, against that of her family was in fact being starved to death in hospital. The grandson is reported to say, "basically they wanted to end her life. The longer they refused to treat her the worse it is for her. It seems to me they feel the best thing would be for her to be allowed to die and I do not think that is right". Being a young man who knows how to deal with matters he went to get a High Court judgment and the High Court judgment was that the hospital really must continue to feed that lady. Whether you think that is right, it is reprehensible or not I still come back to this question of net benefit because I read with some horror ultimately the doctor has the right to make the final decision. If doctors are making that sort of decision how can it be in the net benefit of the patient?

Dr Wilks: You ask about that case, I do not know the details of it but what I do know leads me to think you are absolutely right in saying it is correct that the case should be reviewed and further consensus should take place, I agree with you on that. I do think it is important to set out a fundamental principle, when we talk about the withdrawing and withholding of any treatment, obviously particularly in the case of life-supporting treatment

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where it is likely or in some cases certain that the withdrawal of treatment will result in or be followed by the death of a patient that that is not the doctor's intention. When I talk about benefit I am talking about a situation where the doctor is saying initially, I do not think that clinically this treatment, whatever it is, is of benefit to the patient, there may be more harm and distress in the treatment being given rather than it being not given. However, that is the first step towards a judgment as to whether it is the patient's view as to whether that would be in their best interests. It gets us back to the point that the more people who give us information about their wishes when they are competent the easier it is to make these judgments when they lack competence and capacity. The absolute central point about a decision that a doctor makes to withdraw any treatment is that the intention is to longer give treatment that has no clinical benefit, it is not with the intention of terminating life. Any doctor who makes a decision that someone's life in common parlance has no value and should be terminated and ends treatment with the intention of terminating life is acting illegally and unethically.

Q278 Baroness Knight of Collingtree: It is a matter of very grave concern not only to me but to a large number of people if your real view is that if there is no discernible benefit to a patient then the patient is in a harmful situation. I think that is something which worries a lot of people.

Dr Nathanson: It is not that we are saying if there is no benefit it is harm, we are saying if there is no benefit you look to see if there is harm. Almost every treatment has both benefits and harms and it is the balance between the two that is crucial, that is what we mean by net benefit, you are looking for a treatment which has more benefits than harm. If there is no benefit then you need to look at what the harm is and if that harm is significant that is when you start to raise the question: is this a treatment that should be continued? No benefit and harm usually means it is a bad treatment. That does not mean no treatment it means look for alternatives. I think that is the first message. The second thing is we do not know anything about this case but the one thing which seems to me is absolutely clear from looking very quickly is that there was not enough communication, not enough time given and not enough discussion. That is the whole process. One of the things we kept talking about today is the importance of communication, spending time, because that is part of the benefit. Part of the benefit is what matters to this individual.

Q279 Chairman: This is a specific case, it is much more the general rule that we are looking for.

Dr Nathanson: The general rule is that is why you have to find out as much as you can about what the patient wants from as much as you know about that patient, including talking to his or her family because they know so much about them. That helps

you to build up the picture so you can then discuss with the family the different ways of achieving the benefits and minimising the harm.

Chairman: I am anxious to get your views on the general authority.

Q280 Mr Burstow: It follows on from this. Given the current state of the law in respect of withholding the withdrawal of treatment materially speaking will this Bill make the process of making those decisions simpler in terms of enabling a decision to be made more quickly or will it make it more difficult for decisions of this sort to be made from the point of view of the clinician?

Dr Nathanson: I do not believe this will affect those decisions at all. The decisions that will be affected, which is much welcomed, is that it will be the patient's view on treatment decisions and treatment choices. I think that is much more welcome. We get some elements of that now through those patients who have completed advanced directives but this will enlarge that process. In that sense decisions that are made will be on a better legal basis but more importantly than that all decisions that are made about choices between treatments will be based on what the patient wants.

Q281 Mrs Browning: On the face of the Bill there appears to be no limitations placed on the types of decisions made by carers under the general authority and it is relegated to the Code of Practice. You have expressed some concerns about that, I wonder if you would like to give us some examples as to why you think this may come into conflict with your own areas of authority in terms of the doctor taking decisions for the patient?

Dr Wilks: I think at the moment partly because there is a certain fuzziness between those different powers and responsibility under general authority because one potentially comes into conflict with another. It is something that the Bill needs to be a little more clear about the limits and the specifics of the different types of authority otherwise I think doctors may feel they are not absolutely sure to what extent their general authority allows the doctor to do things in the patient's best interests that they commonly normally do without any restriction now. That is a very important principle. On the second point to your question, the difficulty of resolving disputes about what the doctor might feel either was best or had authority to do and the existence of any other evidence, such as an LPA, such as an advanced decision is something that needs to be subjected to some kind of resolution process because at the moment we have a situation where that might go straight to court. In most cases if you go to court to reach a medical decision it is usually a sign of the failure of the process. I think we need to see more, if I may say so, in the codes about how these disputes are resolved and a bit more distinction between the types of authority.

Chairman: The only areas we have not covered are dispute resolutions and resource, would you be kind enough to write to us on those issues and any other remarks you wish to make. It has been a very, very helpful session.

7. Memorandum from the British Psychological Society (MIB 817)

The British Psychological Society (BPS) is happy both to offer written evidence to the Joint Committee scrutinising the Draft Mental Incapacity Bill, 2003 (Cm 5859) and to comment on the process of consultation as detailed in the Press Notice of 17 July 2003. Our comments on the substance of the Draft Bill are enclosed.

In respect to the process of consultation, the BPS strongly welcomes the open process of scrutiny and particularly welcomes the opportunity to present written and oral evidence to a Bill Scrutiny Committee. We strongly welcome this development in the legislative process.

In respect to the particular questions related to process posed in the Press Notice of 17 July 2003, the BPS welcomes the consultation process preceding the publication of the Draft Bill. As above, we believe that open debate will strengthen the resulting legislation.

We have only two reservations in respect to the process of consultation. First, we note as a Society that the psychological contribution to this area is under-represented. We feel that psychologists have a wealth of expertise emanating from both research and clinical practice in the field of mental health and incapacity that could be used to improve the legislation.

Second, the time scale from publication of a Draft Bill to the requirement of written evidence and the timetabling of oral evidence sessions has been tight. The BPS welcomes the request for involvement and recognises the need to pass legislation more rapidly given the pace of medical advancements. The BPS, like other learned societies, relies in such circumstances on professional members who are employed full-time by the NHS and Universities. Finding time at short notice for preparing written evidence to a short timescale can be difficult, especially during the summer months.

The BPS is a UK-wide body, and we are strongly represented in Scotland, where our members have been closely involved in the Adults with Incapacity (Scotland) Act both during its drafting and now in its implementation. The BPS believes that the Scottish legislation has many advantages over the Draft Bill. We understand that the Joint Committee intends to invite representation from our colleagues in Scotland. Such compatibility across the UK is, we believe, particularly important in the context of Human Rights legislation.

Please find enclosed our formal submission of written evidence to the Joint Committee on the substance of the Draft Bill. We would, of course, expect to expand on these points in oral evidence.

If there is further material that we can offer to support the Joint Committee, the Clerks or the Department for Constitutional Affairs in this or other matters, please do not hesitate to get in touch.

With over 36,000 members, the British Psychological Society (BPS) is the representative body for psychologists and psychology in the UK. Its Royal Charter charges the Society with national responsibility for the development, promotion and application of psychology for the public good.

The BPS welcomes the publication of a Draft Mental Incapacity Bill. We strongly support the intention to address the needs and rights of vulnerable adults and their carers. However, the BPS believes that changes to the Draft Bill are necessary.

The BPS acknowledges the request to present both written and oral evidence to the Joint Committee as recognition of the scientific knowledge base and practical expertise of psychology. Chartered Psychologists with specialist expertise of working with clinical populations are trained to assess competence in decision-making ability. Our comments are intended to advance two broad aims: to assist in the effective implementation of the Bill, a Bill whose policy intentions we support, and to encourage a coherent and psychologically informed approach to mental health legislation.

We welcome the opportunity to elaborate on all these points (necessarily brief here) in oral evidence. We would particularly appreciate the opportunity to elaborate on Items marked .

1. INTRODUCTION

The BPS recognises that the Draft Mental Incapacity Bill legitimises the allocation of decision making authority to proxies following an assessment of the mental capacity of the individual. This means that the expert assessment of capacity is particularly important: serving as it does the dual goals of protecting the autonomy of individuals who retain capacity and protecting vulnerable people who do not.

2. PRINCIPLES

The BPS welcomed the statement of principle included in the Draft Mental Health Bill (Cm 5538, Part 1 Section 1 subsection 3). We recommend the inclusion of a similarly binding statement of principles in the Draft Mental Incapacity Bill.

The BPS also supports the basic principle of law that people who are able to make appropriate decisions for themselves should be legally entitled to have these decisions honoured. Conversely, we believe that legislation such as the Mental Health Act and the Mental Incapacity Act should apply only if people are not so able to make decisions for themselves.

3. CRITERIA

We recognise that it is legitimate to separate the provisions of the Draft Mental Incapacity Bill from the provisions of the Draft Mental Health Bill. We recognise that the Bills address different needs and that people may require the provisions of the Bills under different circumstances. We further recognise that the criteria for application of the provisions of the Bills will be different.

Specifically, the BPS welcomes the definition of capacity used in the Draft Mental Incapacity Bill. In the context of the principles outlined above, the BPS has recommended that the Draft Mental Health Bill includes a criterion of “impaired judgment” (a position shared by many other interested parties). The BPS therefore believes that care must be taken to ensure proper coherence between the two Bills, and that there should be clarity about the boundaries and overlap between the two pieces of legislation.

4. “FUNCTIONAL APPROACH” TO CAPACITY

The BPS recommends that the Bill should make reference to the need for an operational definition of incapacity to be developed within the Code of Practice. The BPS supports the adoption of the “functional approach” when determining capacity. This is consistent with current practice based on the research evidence derived from scientific studies of psychological functioning and has long been a recognised method used by Chartered Psychologists working with clinical populations.

Such an approach ensures that account can be taken of additional factors not necessarily arising from organic impairment. The BPS notes that in the recent *Masterman-Lister* case the role of psychological factors was highly relevant. These include cognitive differences that may arise from educational factors, the influence of general environmental circumstances, as well as cultural, social, and personal beliefs and values that may impact on decision-making competence and on the consequences of decisions made. In addition, specialist assessment of cognitive functioning may be needed, for example where there is communication difficulty because of physical or language impairment or where there is or may be impairments of reasoning, attention or memory.

5. PROCESS—ASSESSMENT AND DETERMINATION OF INCAPACITY

The BPS welcomes the introduction of a structured approach to the management of issues relating to incapacity. We recognise the need for legislation that incorporates both General Powers and specific powers such as Lasting Powers of Attorney.

The BPS, however, believes that the Bill as drafted lacks necessary specificity in the assessment and determination of incapacity. We welcome the definition of incapacity enshrined in the Draft Bill. At present, however, the Draft Bill lacks a robust, transparent and practical system for determining if, and when, the criteria for incapacity within the terms of the Bill have been met.

The BPS believes that the Bill would benefit from the introduction of a formal process of Registration. We believe that this would better meet the identified aims of protecting vulnerable people and their carers. It would also be more consistent with the Scottish Incapacity Act.

To ensure adequate safeguards and to promote the least restrictive approach, the BPS recommends a hierarchy of decision-making authority, specified in a code of practice. This will ensure that adequate account is taken of potential fluctuations in decision-making capacity, as well as reflect the diversity and complexity of decision-making ability across the domains of health, welfare and finance.

(a) *General Authority*

General Authority would allow family, care staff and professionals to provide routine care; taking account of the overall best interests of the individual, and based upon current healthcare opinion arrived at in good faith. This would allow family members, care staff, and other professionals to make routine day-to-day decisions for an adult with impaired decision-making capacity, for example, for a person with severe dementia or severe learning disabilities, without having to be concerned that they were acting illegally. In most cases this would be uncontroversial and would address all routine care and placement issues. In order to promote joint working among care providers and other professionals, however, a formal care plan should be compulsory.

If, however, a major decision needed to be taken concerning the person’s health, personal welfare, or finances that went beyond routine care, if there was a significant change in the individual’s circumstances, or if there was a serious or life threatening condition, the BPS recommends that the Draft Mental Incapacity Bill introduce a system for formal Registration of the patient with the Public Guardian.

(b) Formal Registration

The BPS recommends that the Code of Practice specify the circumstances in which a formal application is required. These would, we recommend, include:

- need for treatment of a serious or life threatening condition (eg refusal to receive insulin medication in diabetes)
- cessation of such treatment
- unresolved conflicts regarding the best interests of the individual
- “do not resuscitate” orders
- the enactment of Lasting Powers of Attorney
- or otherwise where there is an additional or significant change in the circumstances of the individual.

Examples of this process might be:

An adult with learning disabilities cared for successfully within a community setting using General Powers inherits £500,000. It may then be appropriate to Register the individual in order to ensure not only the protection of their financial interests but also to safeguard the care staff from allegations of improper conduct in relation to the substantial sum.

An Adult with dementia might be faced with serious and life-changing medical decisions. Registration of that person with the Public Guardian would likewise protect the carers from criticism in relation to such decisions.

Finally, a person may make a Lasting Power of Attorney giving financial control of their estate to a relative. It would be reasonable to Register the actual implementation of such control with the Public Guardian to ensure that, as presumed, the person involved indeed cannot legally retain financial decision-making powers.

The process of Registration would also be appropriate where there is uncertainty as to the exact status of an individual, for example, where a person in the early and confused stages of recovery from a brain injury who is having difficulty understanding the treatment and rehabilitation options available and is refusing what is being recommended. In many cases it is clear whether or not the individual has retained capacity, but where this is not obvious or is contested then an assessment as part of the process of Registration would address this issue. Consideration should, however, also be given to the process of the lifting of Registration, in cases where capacity may fluctuate or where an individual is likely to regain capacity.

Care should also be taken to ensure that, in line with the functional approach, capacity is not seen as an all or none phenomenon. People may be unable to make decisions about issues such as disposal of assets, but be able to live independently for example. This means that the process of assessment and Registration will need to incorporate single assessments by single practitioners in some cases, but more complex and multiple assessments in cases where the decision is complex or difficult.

The BPS recommends that the formal process of Registration designates a specific person (or persons) as the carer(s) of the patient. The nature of the decisions requiring the powers of the Incapacity Act—financial or practical arrangements for instance—should be clearly specified. The Registered Practitioner should, we recommend, also be given specific responsibilities regularly to check the welfare of the individual and that the carer has not taken actions that lie beyond the issues originally attested to.

6. REGISTERED PRACTITIONERS

Registration of a person with the Public Guardian as detailed above, should occur on the basis of the written evidence of two Registered Practitioners. These would be senior practitioners falling within a description specified by the appropriate Minister in regulations.

Chartered Psychologists with appropriate competencies, experience and seniority would clearly be appropriate for such a role (especially for more complex and sensitive issues). The BPS believes that to obtain reliable and valid assessments there must be additional appropriate training for all registered practitioners.

7. ADVANCE DECISIONS

The BPS supports the inclusion of advance decisions in the Draft Bill. However we recognise that these issues are highly complex.

The BPS remains concerned about people whose capacity fluctuates or where decisions need to be made during a period of slow recovery of capacity. Precipitate and irrevocable decisions about incapacity may therefore be invalid. Formal processes of Registration may address this issue if such processes incorporate regular review, oversight and specificity of planned actions or decisions.

Recent research indicates that people who have previously expressed a desire to end their lives in circumstances relevant to the use of the Incapacity Act are later grateful that they remain alive. A simple “balance of probabilities” model for adjudications (Part 1 Section 3 subsection 2) may be inappropriate. Consideration should be given to a weighted approach, safeguarding against taking irrevocable decisions.

The BPS therefore recommends that Registered Practitioners (referred to above) be called upon to assist individuals in drawing up advance decisions. Chartered Psychologists will have particular expertise here. The BPS also recommends that the Draft Bill includes a clause making it a criminal offence to ignore or destroy an advance decisions. Finally, we recommend that the Draft Bill further clarifies the form of advance decisions and the processes by which they are drawn up, recorded and stored.

8. LORD CHANCELLOR’S VISITORS

The BPS believes that Lord Chancellor’s visitors have an important role to play. In particular, Visitors may have an important role in the process of Registration if the issues raised are particularly complex or involve controversial interventions or disputes. Chartered Psychologists may have particular expertise in this area, but are clearly not “medical” practitioners and as drafted, the Bill (Part 2 Section 49 subsection 2 paragraphs a and b) would exclude Chartered Psychologists from the category of Medical Visitor. The BPS recommends that a third category of Lord Chancellor’s Visitors be created, that of Expert Visitors, in which psychology would be included along with other professions including the law. We further propose that the power to call for reports given to Medical Visitors (Part 2 Section 39) be extended to such Expert Visitors.

9. “BEST INTERESTS”

The BPS supports the “best interests” criterion but emphasises the need to enshrine in law (in line with the Scottish Incapacity Act) the importance of the psychosocial aspects of a person’s life, in addition to medical matters. This would entail assessing the social, psychological, cultural and spiritual aspects of the decisions at issue. Individual beliefs, values and social circumstances should also be taken into account. Again, the precedent of the Masterman-Lister case is relevant here, where the role of psychological factors was considered highly relevant.

10. OVERSIGHT

The BPS recommends that the new Commission for Mental Health (proposed in the Draft Mental Health Bill) should be renamed, and should oversee the proper enactment of both the Incapacity and Mental Health legislation.

11. SCOTLAND

The BPS broadly welcomes the definitions and processes in the Adults with Incapacity (Scotland) Act. Our colleagues in Scotland have considerable experience in that respect, which will prove useful in respect to the present Draft Bill.

12. FINANCIAL CONSIDERATIONS

The proposals in the Draft Bill, and those recommended by the BPS, will require additional resources for initial and ongoing training in assessment, intervention and monitored practice. The objectives of the Draft Bill will be best met if public funding is made available for remuneration for practitioners and Legal Aid for the person without capacity, or their representative. Fees guidance will be required, as will guidance on the length of time needed for proper assessment.

13. ADDITIONAL CONCERNS

The BPS believes that further consideration should be given to a number of further issues:

The BPS remains concerned that the definition of incapacity in Section 2 of the Draft Bill does not fully recognise those people who have communication or memory problems but who function well with appropriate support aids. This may necessitate proper assessment (including clinical neuropsychological assessment) and the use of memory and communication aids and/or interpreters for those who appear to have difficulties in making decisions but in fact are capable given the right level of assistance. The BPS recommends that Section 2 subsection 3 of the Draft Bill be strengthened in this respect.

The BPS is concerned by the term “any form of care” in Part 1 Section 6 subsection 1. This appears imprecise. The BPS recommends that this be reworded as “It is lawful for a person when caring for an individual”. It may be unnecessary, here, to introduce the reference of “P”, when the pronoun “he” is used previously.

The BPS notes a contradiction in drafting between Part 1 Section 17(c) and Part 1 Section 20(2a).

The BPS remains concerned about the impact on individual cases of the excluded groups of decision making (Part 1 Section 26).

The BPS is concerned over the specific relationship proposed between the Draft Mental Incapacity Bill and the Mental Health Act 1983 (Part 1 Section 27).

The Draft Bill should include a system for informal disputes resolution.

August 2003

8. Memorandum from the Royal College of Psychiatrists (MIB 824)

- The Royal College of Psychiatrists is the leading medical authority on mental health in the United Kingdom and the Republic of Ireland and is the professional and educational organisation for doctors specialising in psychiatry,
- The principles which underpin the Mental Health Bill should be similar to those which underpin the Mental Incapacity Bill. A person's decision-making ability is key to both Bills.
- We welcome the respect for self-determination which guides this legislation and that "capacity" is decision-specific and should be assessed on the basis of a person's ability to make a specific decision at a particular point in time.
- The concept of the "General Authority" is to bring into statute common law. However further guidance is necessary as to its scope. Whilst Clause 26 gives some exclusions it does not state the limitations with respect to health care eg sterilization or termination of pregnancy?
- Advance decisions to refuse treatment may cause individuals unintended distress, harm and prolonged suffering. There should be a duty on professionals to try and ensure that an advance decision is not leading to unintended harm.
- Patients should be given the right, which must be taken into account, to express positive wishes about how they wish to be treated. Such wishes cannot be binding upon the health professional. Attorneys or Court appointed Deputies should not have the authority to require a health professional to provide any particular specified treatment, as opposed to the power to refuse consent. The donee should be legally responsible for acting properly in the best interests of the patient.
- "Fundamental healthcare" should not require specific authority. Nor should general medical examination and continuation of long-term treatments to which the patient consented whilst still capable.
- The relationship between the Mental Health Act 1983 and the Mental Incapacity Act will need further clarification. The meaning of Clause 27 lacks clarity. It would be inordinately restrictive and inappropriate if it meant that all incapable people requiring medical drug treatment for mental disorder would need to be detained under the MHA regardless of the circumstances. The majority of treatments for mental disorder should, if "reasonable" and "necessary" be possible under the "General Authority" of the Bill.
- Many people need medication for physical ill health problems. Sometimes cognitive impairment leads to them resisting medication for their physical ill health. A legal mechanism is essential to enable such necessary medication to be given compulsorily when it is "refused" in these circumstances.
- Clause 27 might be replaced with a Clause on treatments requiring specific regulation. A list of interventions not covered by the "general authority" might be broader than that which could not be authorised by a donee. A person who has specifically given authority for another person to make health care decisions for them would surely expect the donee's consent to carry almost as much weight as their own.
- The means by which specified medical treatments will be authorised will depend on the nature of the intervention. Eg sterilization requiring the authority of the Court. Specified treatments for mental disorder could be dealt with by requiring use of the current, or future Mental Health Act. The College's preferred option would be that the "second opinion" process could mirror that used in the MHA (current and future) using the same system and personnel.
- Consideration could be given to expanding the "second opinion" system to include physicians, surgeons and other medical specialists to enable statutory "second opinions" to be required and authorised for a range of difficult or controversial treatments.
- The Bill omits the issue of research involving people who lack the capacity to consent. This is an ethically difficult area.
- Registration of a Lasting Power of Attorney for loss of capacity by the donor in only one area may lead to the Attorney being given wide powers over many areas.

- The present formulation of “best interest” would permit families to insist that their older relative must “go into a Home” in their “best interests” when the older person does not wish it and their difficulties managing at home can be readily overcome by sufficient support.
- Clear guidance should be given as to when the Incapacity Act or Mental Health Act should be used. People should not readily be subject to both Acts.
- Guidance is required, perhaps in the Code of Practice, in relation to the practice of giving “covert” medication.
- The Mental Health Act Commission or its successor body might be given a monitoring role.

1. INTRODUCTION

1.1 The Royal College of Psychiatrists is the leading medical authority on mental health in the United Kingdom and the Republic of Ireland and is the professional and educational organisation for doctors specialising in psychiatry. This report has been prepared in consultation with the Mental Health Law and the Parliamentary Liaison Sub-Committees of the Royal College, with particular reference to the Faculties of Learning Disabilities and Old Age Psychiatry.

1.2 There has been an extensive period of consultation from the time of the original Law Commission reports to the publication by the then Lord Chancellor’s Department of “Who Decides?” and “Making Decisions”. We welcome this opportunity for pre-legislative scrutiny but question the need for such a rapid response given the fact that no Parliamentary time has been allocated for this Bill at present.

1.3 We recognise that a serious gap exists in law in England and Wales with respect to those adults who through the presence of a mental disability may lack the capacity to make decisions for themselves. Whilst case law has increasingly filled this gap and has provided practice guidance, this is unsatisfactory. The absence of statute law has meant that there is neither a ready appeal mechanism, where there are disagreements (as indicated by *L v Bournemouth NHS Trust*), nor a defined basis for developing good practice, such as would be the case with a Code of Practice accompanying a Bill such as this. We commend the Government for this proposal, which will put right this “gap” in law, as stated by the Law Lords in the above case.

2. GENERAL COMMENTS

2.1 Before commenting in more detail about the proposals set out in the Bill we wish to make some more general points that we believe are important when considering the Bill as a whole and in the broader context of other present or impending legislation.

2.2 This Bill is in essence concerned with substitute decision-making under those circumstances where an individual’s decision-making ability (capacity) may be affected by “an impairment of or disturbance in the functioning of the brain or mind”. This concept of making a decision on behalf of another person is important in two other contexts. Firstly, the present Mental Health Act and the proposed Mental Health Bill deal with a very similar issue, although primarily limited to decisions about admission and treatment for psychiatric disorder. The College has argued that the principles which underpin the Mental Health Bill should be similar to those which underpin the Mental Incapacity Bill. Thus, a person’s decision-making ability is key to both Bills. We very strongly urge that the Mental Incapacity Bill should be considered by Parliament first and that there should be very close liaison between the relevant Government Departments with respect to both of these two Bills. Secondly, the proposed new Sexual Offences Bill also includes the concept of a person’s “decision-making capacity” and therefore there should be agreement as to definitions etc. between these two proposals.

2.3 The central principle enshrined in this legislation is that of respect for a person’s autonomy, and right to make decisions for him/herself, whilst recognising also that for some people the presence of a mental disability may render them less able or unable to make such decisions for themselves. There has, therefore, to be a solution in law that enables a resolution to such dilemmas and an alternative approach to decision-making under such circumstances. We welcome the fact that respect for self-determination guides this legislation. We also support the view, now well established in case law, that “capacity” is decision-specific and should be assessed on the basis of a person’s ability to make a specific decision at a particular point in time. This “functional approach” is much to be preferred—it is no longer acceptable to argue that people lack capacity simply because they have a particular mental disorder (eg, dementia, learning disabilities, schizophrenia). However, in law, ultimately, the concept of a person’s decision-making capacity requires that it is either present or absent. In practice such a functional approach may well not be so clear cut. For this reason we argue that both with respect to the determination of a person’s capacity and when considering what is in a person’s “best interests”, if he/she lacks capacity, the legislation should be “enabling” rather than “restricting”. In this regard we welcome the emphasis on using other means (eg pictures, sign language etc) to maximise the possibility of enabling a person to show capacity and the fact that, even if a person may lack capacity to make a particular decision, it is crucially important to take heed of what views he/she is able to express, any past wishes of the person concerned, and the views of others who know the person well.

2.4 We note that the Bill as it stands does not include any mention of a person having a “mental disability” or “mental disorder”, rather that there must be evidence of “an impairment of or disturbance in the functioning of the brain or mind”. The College is, in principle, supportive of this change as it moves from a categorical approach (ie using the label of a mental disorder) to a functional approach addressing the individual’s cognitive/emotional state but would emphasise two points. Firstly, clearly what is in effect a loosening of the definition from earlier proposals should not lead to the challenging of capacity of those without any obvious impairment or disturbance. Secondly, there are many very different ways in which a person’s mind or brain might be affected such as to impair his/her decision-making capacity. Some problems, such as dementia, primarily affect cognitive ability and memory and are progressive. Others, such as schizophrenia and manic/depressive disorder, may be intermittent and affect reasoning ability. Yet others, such as drug abuse and alcohol intoxication, may result in a temporary confusional state, or, if associated with dependence, result in thinking that may be dominated by the demands associated with cravings and withdrawal. Impairments such as learning disabilities may be lifelong but abilities will be affected by educational and other opportunities. Thus, we would argue that any assessment requires a two-stage procedure. If a person’s capacity is in doubt it is necessary to establish whether he/she does or does not have an impairment or disturbance of mind or brain and also to establish whether this has functionally affected his/her decision-making capacity for that particular decision. What then follows will depend very much on the individual situation and on the seriousness, and the urgency, of the decision to be made. The potential range of situations in which such legislation would be relevant has implications for the concept of “the general authority”, and for the Code of Practice (see below).

3. SPECIFIC COMMENTS

3.1 We appreciate that the concept of the “General Authority” is to bring into statute what is at present common law practice. However, some further guidance is necessary as to the limits of this Authority. Whilst Clause 26 gives some exclusions it does not state the limitations with respect to health care. What about such contentious issues as sterilization of an incapacitated person or termination of pregnancy?

3.2 There is nothing in the Bill to guide with respect to research involving people who lack the capacity to consent. At present this is an ethically difficult area. There is clear guidance from, for instance, the Medical Research Council and the Helsinki Convention but common law does not strictly provide such authority, as it cannot be argued that research is necessarily in that incapacitated person’s best interests. However, if legal mechanisms prevented or deterred research with such people, then the development of treatments and the undertaking of treatment trials for disorders such as Alzheimer’s disease would be very problematic. Section 51 of the Scottish Incapacity Act provides a framework for research which the College would support.

3.3 Advance decisions to refuse treatment may sometimes lock individuals into courses of action which may lead to distress, harm and prolonged suffering which they had not intended. Refusal of active treatment in severe dementia, for instance, might be interpreted as debarring treatment for a urinary tract infection, or the good management of co-incidental stroke, with the result that the patient does not die but suffers considerably and unnecessarily. This makes safeguards to test the validity of advance decisions to refuse treatment important. The emphasis in legislation should be to put a duty on doctors and other professionals to ensure that such an advance decision is not leading to unintended harm and, if this was occurring, a mechanism to clarify or set aside the decision should be available.

3.4 It is appropriate that patients be given the right to express positive wishes about how they would want to be treated in advance as well as the right to refuse treatments in advance. Such wishes must be taken into account when determining “best interest”. They cannot, however, be binding upon the health professional (otherwise a doctor might be required to give treatment to a patient which he knows to be harmful).

3.5 It is crucial that the donee of continuing powers of attorney be made responsible for acting properly in the best interests of the patient, and that there be clear safeguards and processes for when this may not occur. There has been concern about donees under the existing EPOA procedure (as well as advocates perhaps) failing to act truly in the best interests of patients. There is a need for strong safeguards in the Bill against donees failing to carry out their responsibilities properly. An addition under Clause 12 (5) could be made to address this:

12 (5) (e) evidence that the donee is not acting in the best interest of the incapacitated person or is failing to carry out the proper responsibilities of the donee.

3.6 The general principles of benefit, minimum restriction of freedom, past and present views of the adult, the views of others, encouragement to use existing skills and to develop new skills (which have all been employed in the Scottish Incapacity Act) are all very important and should receive prominent attention. This formulation could be less paternalistic than the present proposed “best interests” statement.

3.7 There could be an issue, in judging capacity, about retaining “the memory of decisions”. The best view may be that memory of the necessary information needs to be retained long enough to make a decision, and that there be consistency of decision-making, such that the person makes the same decision each time, given the same information, and/or agrees with the decision when reminded of it.

3.8 Concerns have been expressed that medical treatment under the Incapacity Act has proved a problem in Scotland. This is largely because of the burden of administration and bureaucracy on the professionals. Nonetheless, the Bill must give sufficient protection. Consideration will need to be given to what treatments are regulated and which can only be administered with a statutory second opinion. A narrow definition of medical treatment, with a need to certify incapacity and a record of consultation for “written consent” treatments, may be appropriate.

3.9 Many areas of medical treatment will be dealt with under the General Authority, or through appointed proxy decision-makers, with the opportunity to seek resolution from the Court in contentious cases.

3.10 It seems appropriate that basic care, or “fundamental healthcare”, should not be subject to the need for any formal procedure under the Act (as argued by Lyons, D.). This should include basic nutrition, hydration, skin care, oral care, elimination, eyesight and hearing integrity, communication, mobility and simple measures to relieve pain or discomfort. It could be argued that it should also include general medical examination and continuation of long-term treatments to which the patient consented whilst still capable, such as for diabetes, heart disease, etc.

3.11 Beyond this, there should be a Medical Treatment Plan for people with significant incapacity which is subject to annual review.

3.12 This could be linked to the expectation that for a reasonable period of time, (perhaps three months) whilst a test of best interests would be required, there would be no need for any formal mechanism for the approval of apparently necessary treatment.

3.13 The relationship between the Mental Health Act 1983 and the Mental Incapacity Act will need further clarification. Clause 27 asserts the supremacy of the MHA. It is unclear if clause 27 refers only to people who are already detained under the MHA or if it includes all people who require treatments regulated under Part IV of that Act. That is, the draft Bill is unclear about treatment for mental disorder in incapable people not resisting treatment and not seeming to need detention. It could be taken to imply that psychiatrists (and social workers and general practitioners, in collaboration with family and carers) should formally detain all incapable people requiring medical drug treatment for mental disorder, regardless of the circumstances. Most incapable people would be at home or in nursing/residential homes. Such a practice would seem inordinately restrictive, inappropriate and excessively bureaucratic. The majority of treatments for mental disorder should, if “reasonable” and “necessary” be possible under the “General Authority” of the Bill. They would require safeguards but not necessarily detention under the MHA or the involvement of psychiatrists.

3.14 Where an incapable person actively resists or opposes necessary treatment for mental disorder, there should be absolute clarity as to what legal procedure may be used to cover the situation and which law (eg this Bill or a Mental Health Act) has precedence. At present this appears to be the MHA. Arguably, a briefly and swiftly acting order, or mechanism, may be necessary for a single and perhaps urgent health intervention. This might mean the appointment of a Deputy by the Court but, again, there should be both capacity for the procedure to be delivered in a very timely fashion and clarity as to what powers could be bestowed.

3.15 Many older people need medication for physical ill health problems. Sometimes cognitive impairment causes them to resist medication for their physical ill health. A legal mechanism is essential to enable such necessary medication to be given compulsorily when it is “refused” in these circumstances.

3.16 Given the foregoing reservations about interactions with the Mental Health Act, in Clause 27, it may be more appropriate to omit it and replace it with a Clause on regulated treatments, perhaps using the recommended list of treatments under the Adults with Incapacity (Scotland) Act 2000. Consideration may be given to having two lists of regulated treatments. The list of interventions not covered by the “general authority” would be broader than that which could not be authorised by a donee. A person who has specifically given authority for another person to make health care decisions for them would surely expect the donee’s consent to carry almost as much weight as their own.

3.17 The means by which specified medical treatments will be authorised will depend on the nature of the intervention. Sterilization will presumably require the authority of the Court. Specified treatments for mental disorder could be dealt with by requiring use of the current or future Mental Health Act. This would be cumbersome and expensive. It would also lead to the person being subject to compulsion in a number of areas in addition to having authorised medical treatment. Alternatively a totally separate “second opinion” system could be devised. This is likely to lead to considerable duplication of administration and confusion for professionals. The College’s preferred option would be that the “second opinion” process could mirror that used in the Mental Health Act (current and future) using the same system and personnel. The certificate issued (forms 38 and 39 in the Mental Health Act 1983) would state that the person was subject either to the Mental Health Act or the Mental Incapacity Act (one to be deleted). It is presumed that this would require a clause in the Incapacity Act amending the relevant section(s) of the Mental Health Act.

3.18 Consideration could be given to expanding the “second opinion” system to include physicians, surgeons and other medical specialists to enable statutory “second opinions” to be required and authorised for a range of difficult or controversial treatments.

3.19 Concern arises regarding registration of Lasting Powers of Attorney (LPA). Whilst the Bill makes great play of differential levels of capacity, people who have lost capacity in one area of decision making may still be unimpaired in other areas. However, registration of an LPA appears to be an “all or nothing” event, potentially with loss of capacity by the donor in only one area leading to the LPA being registered and giving the Attorney wide powers over finance, health and welfare. It is noted that health care decisions cannot be made by the donee whilst the donor retains capacity. Nonetheless this area may require greater clarity, perhaps through the Code of Practice.

3.20 Clinicians meet families who are very strident in their views that their older relatives must “go into a Home” in their “best interests” when actually these older people may have dementia of only moderate intensity, such that their difficulties managing at home can be readily overcome by sufficient support. The older persons may be adamantly in favour of retaining their independence. There must be concern that the present best interests formulation risks the danger of over-paternalism in such cases through an undue influence of relatives’ views.

3.21 Mental Illness may lead to loss of capacity in many different ways. Examples include problems with memory (eg dementia) or delusions (eg schizophrenia). It is essential that clear guidance is given as to when the Incapacity Act or Mental Health Act should be used. Ideally people should not readily be subject to both Acts. Nor should the decision to use one or other Act be determined by the age of the person rather than their needs.

3.22 Clause 10 (2) seems to allow an LPA to force someone to receive care or be resident somewhere. How will this happen? Will an appropriate authority to act be required?

3.23 Arguably capacity should always be assessed by a doctor, not least with an LPA. It would seem appropriate that in most people for whom it was felt necessary to register and LPA, or for whom a declaration by the court was needed (clause 15), medical evidence would also be required. It would also seem likely that there would be an increased need for Lord Chancellor’s visitors.

3.24 Imposition of care in the face of resistance is an important area. This would need guidelines jointly with ambulance services and others to make it workable, best outlined in a Code of Practice. The principle that care may sometimes need to be imposed in the face of resistance is important and the Bill should state this. Another area where guidance is required, perhaps in the Code of Practice, is in relation to the practice, prevalent in many nursing homes, of giving medication “covertly”. That is, disguised in food or drink.

3.25 There is a need for quick and simple processes. Too much paper work risks preventing incapable people from receiving the necessary care when they, their carers and professionals are excessively distracted and occupied (or even deterred) by burdensome form-filling. Apparently there has been a perception in the Scottish experience of such a danger, with simple things such as dental checks and flu jabs requiring excessive documentation. Such issues may need to be picked up in more detail with the elaboration of a Code of Practice but it seems important to highlight them now.

3.26 The duty to encourage participation of the incapable person, under Clause 4 (2b), is a most welcome thrust towards promoting autonomy despite diminishing capacity.

3.27 Within the General Authority, Clause 6 seems potentially to allow significant leeway for a person to use the incapable individual’s funds, perhaps abusively, and concern is raised that this may be insufficiently “policed”. The simpler procedure used under the Adults with Incapacity (Scotland) Act 2000 may be both easier to operate and easier to “police”.

3.28 With regard to the welfare powers of Lasting Powers of Attorney, these could include consent to treatment but it would be important that the Bill should lay down absolute clarity about the role and power of Attorneys in this area and whether additional certificates or other forms of permission might be needed.

3.29 With regard to Court appointed Deputies, there is a need for clarity as to whether such appointments would have to be made in every case for any decision or whether they may only need to be invoked when the incapable person resists the proposals or when in other ways there seemed to be controversy. Apparently in Scotland this area has been interpreted in different ways in different parts of the country, with some areas taking the line that all decisions require such a Court appointment. This approach would seem highly cumbersome, likely to delay timely intervention in the best interests of the individual concerned, and extremely costly of Court resources.

3.30 There should be clarity that any Attorney or Court appointed Deputy cannot have the authority to require a health professional to provide any particular specified treatment, as opposed to the power to refuse consent.

3.31 With regard to the exercise of Powers by Attorney or Deputies, it is not clear how concerns about the use of such powers might be relayed to the Court. Indeed, relaying concerns to a Court may be a mechanism that is too cumbersome for use when there appears to be some urgency. Perhaps the complaint or area of concern should in the first instance be looked into by either the local authority Social Services Department or the Public Trust Office (or equivalent) to establish swiftly whether there are grounds to merit further procedures.

3.32 A framework under public law to protect incapable people from neglect or abuse, in their own homes or in institutions, seems very necessary. It is hoped that Clause 31 will provide the basis for this. The College would welcome the Mental Health Act Commission or its successor body being given a monitoring role similar to that of the Mental Welfare Commission in Scotland.

August 2003

Witnesses: **Professor Glynis Murphy**, Professor of Clinical Psychology in Learning Disabilities, **Dr Karen Ehlert**, Honorary Secretary of the Division of Clinical Psychology, **Dr Peter Kinderman**, Reader of Clinical Psychology at the University of Liverpool, **Dr Catherine Dooley**, Consultant in Clinical Psychology, **Dr Camilla Herbert**, Clinical Psychologist specialising in neuro rehabilitation, British Psychological Society and **Dr Tony Zigmond**, Consultant in General Adult Psychiatry at Leeds Mental Health Trust, Royal College of Psychiatrists, examined.

Q282 Chairman: Thank you all for attending. I think you heard the announcement I made to the previous witnesses, would you be kind enough to introduce yourselves briefly.

Professor Murphy: I am Professor Glynis Murphy, Professor of Clinical Psychology and Learning Disability at the Tizard Centre.

Dr Ehlert: I am Karen Ehlert, I am from the British Psychological Society and I am the Honorary Secretary of the Division of Clinical Psychology.

Dr Kinderman: I am Dr Peter Kinderman Reader in Clinical Psychology at the University of Liverpool. I Chair the British Psychological Society's Working Group on Mental Health Law Reform.

Dr Dooley: I am Dr Catherine Dooley, I am a Consultant Clinician Psychologist working with older people in South London. I am also the Clinical Convener for the BPS Group developing professional guidelines on the assessment of capacity for psychologists.

Dr Zigmond: I am Tony Zigmond, a consultant psychiatrist in Leeds. All my patients are currently detained under the Mental Health Act. I am the Mental Health Law Reform lead for the Royal College of Psychiatrists.

Dr Herbert: I am Camilla Herbert, I am Chair of the Division for Neuropsychology in the British Psychological Society and I work in brain injury rehabilitation.

Q283 Chairman: If I can start, as you know the draft Bill will put into the statute a number of principles that are already in the common law but it also establishes a new system relating to substitute decision making. In your view does the draft Bill go far enough to improve the decision-making process for professionals, families and carers and those who are unable to make decisions for themselves? Does the draft Bill place enough emphasis on the need to facilitate communication by people with incapacity?

Dr Kinderman: Broadly, yes. Like everyone else we welcome the Bill. We think in its basic structure it is very good. We obviously have some concerns, you have had some written submissions about some of the concerns we have. With respect to making and communicating decisions one of the things that we generally believe is there exist quite a few codes of practice, especially the British Medical Association's code of practice drawn up with the Law Society. If the Bill were to make reference to a code of practice which enshrined those principles then broadly the Bill would meet many of the requirements that we have.

Q284 Chairman: Are you saying that the principles should be in the code of practice?

Dr Kinderman: You asked me in the second question about the draft Bill placing emphasis on the need to facilitate communication. In that respect, the guidelines drawn up by the British Medical Association and the Law Society are very good. If reference to them are made in the Bill then yes the Bill has many of the attributes we would want in it.

Professor Murphy: We would also like to see a statement of principle at the beginning of the Bill, much like in the Scottish Act: "All decisions made on behalf of an adult with impaired capacity should benefit the adult and take account of the adult's wishes if these can be ascertained, take account of the views of relevant others . . . restrict the adult's freedom as little as possible . . . and encourage the adult to use existing skills or develop new skills", and that would include communication skills.

Q285 Chairman: You do not see any conflict if the principles are on the face of the Bill and the functional approach that is in the rest of the Bill?

Dr Ehlert: Not at all.

Q286 Chairman: You do not see any conflict?

Professor Murphy: I do not believe those principles will conflict.

Dr Zigmond: One of the advantages and disadvantages of putting things in statute is that it improves clarity but of course it makes the boundaries much more certain. There are certain areas where it seems to us that there may be some difficulties, and if I can very briefly mention three: One would be patients who wander, not particularly trying to get somewhere but they wander. What happens if the nurse keeps directing them? As you know at the moment there are many examples where doors have two handles or some other system which in some ways does restrict a person's movement. The way that it is expressed at moment it is unclear as to how that would be dealt with. A second would be bathing, somebody who just pushes everybody away all of the time, what does one do about that basic care? Is that prevented by this Bill with the wording it has now or is it not? A final example relates to an area of difficulty which is where one is treating people for a physical disorder but they suffer from incapacity. Supposing one has a patient with mild heart failure or who needs antibiotics and they are just pushing people away where would the authority be or would it not be and can one then revert to common law to give that treatment? It is those sort of areas where there are some concerns.

8 October 2003 Professor Glynis Murphy, Dr Karen Ehlert, Dr Peter Kinderman, Dr Catherine Dooley,
Dr Camilla Herbert and Dr Tony Zigmond

Chairman: What I would like to do now, as we did with the previous witnesses, is to bring up the questions on research. I think you yourselves and the previous witnesses are particularly expert in this area.

Q287 Jim Dowd: My powers of observation would indicate most of you were sitting in the back rows when I asked the questions earlier so I will not go through them in the same detail. What provision should we have in this Bill regarding the involvement of incapacitated adults in research?

Dr Zigmond: I think from the point of view of psychiatrists we take a slightly different view from that which I heard the British Medical Association express. We put a lot of faith in ethics committees, we suspect they need considerably more guidance, which we would want in a code of practice. We have some difficulty with the overall notion that there should never be substitute decision-making. Ethics committees may well decide that a piece of research is very proper and yet I as an individual may say that I want no part in it. I think there probably ought to be a distinction between those types of research, and clearly the research is essential, where there is the ability for substitute decision-making compared to that where there is not. If I can give you an example, if one is doing research over a long period of time perhaps relating to a particular form of learning disability then there should be no difficulty in terms of time anyway in having somebody authorised who would be looking at it from the point of view of the incapacitated individual, even having got an okay, as it were, from a research ethics committee, and I will come back to that. If one was doing research on investigating different treatments within the first hour of admission for people who suffered a head injury one could not then do that research if it introduced substitute decision making because there would be no mechanism for doing that. We thought about how to bring these together, and I am grateful to one of my colleagues here, one option would be, again it would be in the guidance for the research committee, they would have to consider whether or not as part of the protocol for the research there was a requirement for substitute decision-making and the code would give guidance as to how they would come to that decision.

Dr Kinderman: To follow up on that, the answer to the first question is, yes, the Bill should give consideration to the role of research and how people give consent for research. Like Tony we do have some concerns about the idea of having blanket decision making available for everybody. The third point which Tony alluded to is one of the mechanisms. We generally like the role of local research ethics committees and we think they are quite strong and quite powerful bodies that do legitimately constrain research. The way that the legislation could possibly work would be to give guidance to ethics committees on how they offer approval or guide development of the protocols put before them rather than legislate for specific research and take specific actions.

Q288 Chairman: Would they then need to refer to the code?

Dr Kinderman: Yes.

Q289 Chairman: You would do that. There would be some sort of provision in the Bill and some sort of code.

Dr Kinderman: If the Bill were to refer to the need to follow proper procedures in obtaining consent for research and were to refer to the idea that local research ethics committees can give due consideration to the Incapacity Act that would defer the responsibility to the ethics committee not to the researcher. I cannot speak for Tony but I regard local research ethics committees as well constituted, potent bodies.

Q290 Jim Dowd: You covered nearly all of the ground in the series of questions which I had. Research can benefit the individual although in a general sense it is looking further down the track to help others, are you satisfied that we can sufficiently safeguard the individual, let me use the case of those with Alzheimer's, from being exploited in the pursuit of research which is not connected with any research itself of the kind?

Dr Kinderman: My initial response to that is I think local research ethics committees do a good job of protecting research participants against exploitation. At the moment the whole purpose of this Bill is to plug a gap in legislature. I think the structures allow local research ethics committees to address that issue, specifically with respect to incapacity and give people the power they need. Most of my salaried work is doing research on people who have questions of capacity under the Mental Health Act and I think local research ethics committees do a very good job balancing the risks and benefits for those individuals because there are good laws behind them.

Q291 Baroness McIntosh of Hudnall: Can I ask you the same question I asked your British Medical Association colleagues which is about the state of research at the moment and in what way. Including provisions for research within the confines of this Bill will create opportunities or improvements that you do not currently see available? What are the inhibitions to research being carried out now? Dr Kinderman you said you are engaged in research, you are already plugged into your local research ethics committee, you have presumably already presented them with opportunities to consider issues of the kind that would arise. If research were included in the Bill, what is going to get better?

Dr Zigmond: I think many research ethics committees quite properly are very perturbed about this area. I think they are more reluctant to give approval than they would do if there was a clear framework within which they could operate. In fact one of the reasons why I came down to the decision that in many circumstances a research ethics committee should require a substitute decision-maker is again because of the confidence that it

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would give them that this was being done where the balance between what should be extremely minimal risks for the individual who is not able to consent and the potential benefits either for that patient or at least for those with similar conditions is clear. It is really a feeling that this would enable research ethics committee to be more willing to grant permission because of the safeguards. At the moment people are just not sure whether they can or not.

Professor Murphy: Perhaps I can add to that, I know a number of research projects that have been posed in London which were turned down because of the nervousness of ethics committees, especially where it was a sensitive topic such as sexuality. I myself had a great deal of difficulty getting projects through ethics committee that related to providing treatment for men with learning disabilities who committed sex offences. It seemed to me blindingly obvious that somebody should have tried some kind of framework. I think the ethics committee were opposed partly because they were sex offenders and partly because they were men with learning disabilities. They were a bit unclear about exactly how procedures for consent should take place and whether they were sufficient, and so on. I think this will make it all much clearer.

Q292 Stephen Hesford: I want to focus on Clause 27, if I may. Clause 27 in a way works forward and works backward. It works forward in the sense of how does the Mental Health Act relate to this Bill and it works backward in the sense of how does this Bill relate to the mental health legislation. It is that forward and backward relationship that I want to explore. Is there an overlap? Should there be an overlap between this Bill and either the Act or any new form of mental health legislation? If there should be an overlap what should that overlap be? Does Clause 27 adequately express the relationship?

Dr Zigmond: First of all there is bound to be an overlap because within the definition of mental disorder both in the code and the Mental Health Act and the proposed Mental Health Bill almost any common conditions that lead to incapacity are included.

Q293 Chairman: When you say the Mental Health Bill, do you mean the draft Bill?

Dr Zigmond: The draft Bill to come. The draft Mental Health Bill rather than this Bill. The first thing is many patients could be subject to both. The second thing is that as I understand Clause 27 (I think I did not understand it to start with it let me add) I think it is only referring to those people who are currently detained under the Mental Health Act, it is not talking about those treatments which are covered by the Mental Health Act or patients who are not detained under the Mental Health Act. My reason for saying that is that first of all it says in Clause 27 if the giving of the treatment to a patient is regulated unless they are detained under the Mental Health Act it is not regulated by part four. The second reason for saying that is that part four of the Mental Health Act includes not only those

treatments which people commonly talk about with concern such as ECT and medication but also includes nursing care, habilitation and rehabilitation. If it is not referring to only those detained then any nursing care, for anybody who requires it for incapacity would have to come under the Mental Health Act, that is clearly nonsense. The problem then is for many people, professionals, there may be almost a choice as to which act to use. Let me give you an example of some of the difficulties we think that may present. In this Mental Incapacity Bill there is regulation and authority given both for advance statements and lasting power of attorney. If you ended up under the auspices of this Bill then those would be honoured. If you ended up under the auspices of the current Mental Health Act or the draft Mental Health Bill they would not be honoured. That seems to us to put professionals in a very difficult position and to be frankly a nonsense in relation to patient care. I think the second bit that is important in relation to this is the protections that are built into the Mental Health Act which are not built into this. There is a later question about *Bournewood*, I do not know whether you wish me to go into that now.

Q294 Chairman: If you would.

Dr Zigmond: *Bournewood* related to the admission of a patient to hospital but also to his treatment. To separate the two is in fact very difficult, admission includes treatment and related to specific treatments. The Mental Health Act it seems to me gives three particular protections, it protects people because they have a right of appeal, it protects people because of a system for second opinions, statutory second opinions where the doctor is not choosing which other doctor to go to give a second opinion, and in some circumstances it is not only a medical second opinion. Thirdly in terms of the inspectorate in the form of the Mental Health Act Commission. This Incapacity Bill certainly puts in if not a right of appeal then a system for dispute, which I will call a right of appeal. It puts in some inspectorates but there are questions about how far that goes. It has no system for second opinions. Patients who for example are in a nursing home and require treatment, medication for their mental disorder would continue to get it. According to this Incapacity Bill if patients continue to be compliant they could be given the ECT without the use of the Mental Health Act or any of the protections which Lord Stein said were missing. If one looks at the draft Mental Health Bill, the new proposed Bill chapter five in there addresses some of these issues only for patients in hospital, not for patients either in nursing homes or in the community. There continues to be very big omissions in our view.

Q295 Stephen Hesford: Dr Kinderman wanted to say something.

Dr Kinderman: You mentioned forwards and backwards in terms of the relationship between the two Bills. There are specifics and generalities. Tony has talked about one of the specifics, which are that

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weaknesses need to be tidied up. There is also an issue that both the Royal College of Psychiatrists and the British Psychological Society have about relationships between the two Bills. Although they deal with overlapping areas of mental health, and they both deal with proxy policy decision-making there are many quasi medical decisions made on behalf of patients who cannot make decisions for themselves, we both have concerns about that. One of the things we like about this Bill is it essentially validate people's decisions made when capable. It says that the junction between allowing somebody to make a decision for themselves and stepping into to making a decision for them is based on incapacity. We are concerned that the basis of the Mental Health Bill it effectively the same issues, so in the feed forward and the feedback between the two bills there is a disparity in approach taken in the two bills. On balance although the specifics of this Bill need to be looked at the approach of validating the consensual wishes of somebody who is incapable of making decisions is one that we approve of.

Q296 Stephen Hesford: As I recall it the two bills in Scotland do a similar job, they both contain the same set of principles so they are not necessarily parallel but separate. Are you saying that something ought to be done either to this Bill or outside this Committee something to the draft Mental Health bill, and if so what is it, to make the relationship more symbiotic from a practitioner's point of view?

Dr Kinderman: There are three elements to that, the first answer is yes. The second answer is in part it does relate to the Mental Health Bill but in part it relates to the statements of principle, which are certainly ones that we at the Psychological Society believe. We believe that the law should rule that if people are able to make decisions for themselves unimpaired by mental illness in the case of the Mental Health Act or unimpaired by mental incapacity of the sort of conditions we are talking about for the Mental Incapacity Act they should be allowed to do that. One of the differences between the Bills is that this Bill is welcome. If people really are unable to make decisions for themselves somebody has to make the decision for them and we will clarify the law on that point. One of the difficulties of the Mental Health Bill and one that concerns us and the Royal College of Psychiatrists is that it takes a different approach to the question of whether the law can intervene in people's lives.

Q297 Stephen Hesford: In terms of Clause 27 what would you do, if anything, because I have not heard anything, that would address any of the issues that we have been speaking about?

Dr Zigmond: Let us try and be specific in relation to the general authority. One of the questions that you have asked is, what should be excluded? What should not be covered by the general authority? That is for discussion. If I can give you some examples, in order to build in the *Bournewood* type protections one would warrant in relation to treatment for mental disorder there were mirrored protections,

there were similar protections to those in the Mental Health Act. One would not want to set up a completely separate system so again if I may just paint a simple picture for you, if you have a patient who is requiring medication for mental disorder, after an equivalent length of time as under the Mental Health Act there should be a second opinion. How could one do it? One could have a second opinion process under the current Act or whatever comes under the new Act, you could have that accessed by two acts rather than one and that would keep duplication to a minimum, training to a minimum and bureaucracy to a minimum. That is one thing, there are others. We think that there are questions as to what invasive medical treatment should come under the general authority. If there are considerations there then one of the things one could do is have a second opinion, have a range of medical professionals and adults. Again to give an obvious example if it is thought that somebody needs a lot of teeth removed is it right that it goes under the general authority or should one at that point have a requirement that somebody else skilled in that work would be brought in independently to confirm the clinical advantages of this? It is building on this. That would of itself mean that in terms of *Bournewood* it would address those gaps. We think we would go further because it would bring in other branches of medicine and stop some of the discrimination between psychiatry and other branches of medicine.

Q298 Mrs Humble: I want to clarify if could there be a harmonious situation that Stephen was talking about between any mental health legislation and this legislation. On that issue of compulsion that you referred to, which does seem to be a very distinctive part of mental health legislation and at variance to everything that is in this draft Bill. I just wonder if there is any way that we can overcome that?

Dr Zigmond: One of the difficulties is the notion of compulsion. It can certainly be argued that if somebody truly lacks capacity are they refusing anything, are you compelling them any more if they can no more refuse than they can consent. As I say this is one of the difficulties. For example in some very ordinary situations can you compel somebody not to go into the road, you can because that would be immediately dangerous, but it is less than that. This Bill presents those difficulties. There are those of us who believe that a Mental Health Act, (believe very strongly I have to say) should not be forcing anything, any intervention on people who are able to make decisions for themselves. That is a route that they have gone down in Scotland and we would very much like to see the basis of that. We would go further and say in an ideal world—I was advised not to say this but as you have asked the question I will—we think there should be two bills but not these two. We would have an Incapacity Bill very much based on this but with the protection that I just hinted at which would cover all people who lack capacity for whatever reason and then it is true that that would not cover certain groups of people who

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have committed offences but we would have a separate Mental Disorder Offenders Bill, we would have two but not these two.

Q299 Mrs Humble: Would you also recognise the fact that within this draft Bill it is recognised that sometimes people who will be making decisions whilst they are capable for a future time when they will lack capacity which you as clinicians may not agree with, the family may not agree with, carers may not agree with but those decisions will hold, whereas when you are dealing with your patients who are confined under the Mental Health Act you are making decisions on their behalf and they may well be expressing opinions that they are totally opposed to what you are doing to them. I have real difficulty trying to come up with a situation where we can harmonise those two.

Dr Zigmond: I think it could be harmonised. Leaving that to one side can I say that I would not want this to detract from building in the protections that I talked about.

Dr Kinderman: Tony and I very much see eye to eye on this. Is it possible to come up with a situation where we look out at the world and see nothing but fluffy bunny rabbits? No, there is always going to be difficulty out there. A big question is, like Tony says, is the issue about two Bills but not these two Bills. There are a number of options. There are a couple of things that are important, there could be better harmony between the two bills, both Tony and I are making some percentage of our evidence today about the relationship with the Mental Health Bill. The way this current Incapacity Bill is structured has the safeguards that Tony mentions but the basic principle, and this is one of the reasons why we would like the principles to be on the face of the Bill, the principle that people who are able to make decisions for themselves should have those decisions respected is one that we welcome. Introducing that into UK law would only go some way towards harmonising the issue. The reason why I see people who are treated compulsorily under the Mental Health Act and the reason why Tony treats people under the Mental Health Act is because they are not able to make valid decisions about their health care, their health care is perturbed and disturbed by their mental disorder. It is not dissimilar to the reasoning behind the Mental Incapacity Act because you are not making valid and consensual decisions so decisions are perturbed by the mental disorder. It is in the realm of the incapacity legislation in general to say that a proxy decision has to be taken about the validity of the health care. It is also the case that many of the people detained under the Mental Health Act I have seen for research purposes are perfectly able to refuse participation in research and I have to by law accept that refusal, I cannot say because they are mentally ill they have no rights under law.

Q300 Mrs Browning: Can I bring you back to the *Bournewood* case, some of the problems that occurred there were that carers who did have

capacity and who were able to speak for that individual were rejected by the professionals and had they had more input earlier we would not have needed what was described as medication and then after a period of time a second opinion. I can see the strength of having the opportunity for an independent medical opinion so long as when you are dealing with people with autistic spectrum disorders the person giving them the second opinion actually has a specialism in the subject. This is the real problem that we have, we are talking about conditions like ASDs, which come under the remit of psychiatric services and inpatient treatment but there is a paucity of psychiatrists in this country who are actually able to deal with a combination of either autistic behaviour, which is not a psychiatric condition but is what a lot of us would regard as fairly normal autistic behaviour however challenging and those people with an ASD who do have an overlying psychiatric condition. How do you see this draft Bill specifically helping cases such as the *Bournewood* case?

Dr Zigmond: I agree with everything you say. The only thing I would add is there is a shortage of psychiatrists in this country not just in that particular area.

Q301 Mrs Browning: Good plug.

Dr Zigmond: I agree entirely. One of the things that we tried to do when I served on the relevant bit of the Mental Health Act Commission which addressed issues not only of those where there could be expertise in particular areas and the importance of trying to match people with expertise but also looking at race and gender because we also thought that was important. They are important but whilst we have the shortages that we have it is very difficult to ensure that the highest standards we wish for are always met. I agree with everything you say.

Q302 Mrs Browning: Are the resources and lack of trained psychiatrists going to have as much an impact on this legislation as they are having under the general mental health services and the Mental Health Act?

Dr Zigmond: Except that much of this legislation of course is not relating to psychiatric care.

Q303 Mrs Browning: I realise that.

Dr Zigmond: But where it does, yes, it will.

Q304 Baroness Knight of Collingtree: I ask this question as much to get it on the record as to ask your opinion of it. It is my understanding that many mental patients' conditions, particularly those with psychiatric worries, vary greatly according to whether they take their medication or whether they do not take their medication. In other words, there are times when they are perfectly logical if they have taken their medication and times when they are not. Could we cover this point? Am I right or wrong on this? How do you deal with it?

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Dr Zigmond: You are right. I am not quite sure what it is you are asking. As a statement you are right, that many patients with many disorders are well if they take their medication and poorly if they do not.

Q305 Baroness Knight of Collingtree: But we are dealing with psychiatric patients and mental patients.

Dr Zigmond: They would be no different from somebody with epilepsy or diabetes. It is really rather stigmatising I think to pick out one particular group because it applies to most people who have chronic conditions which require medication. If they do not take the medication, they will be poorly. Some of those will have their decision-making ability markedly damaged—an obvious example is diabetes—if they do not take their medication. One needs to be careful about singling out one group.

Q306 Baroness Knight of Collingtree: This is the Mental Incapacity Bill and so that is why I am talking about that particular group. I do not mean to stigmatise them.

Dr Kinderman: One of the issues which follows from that is that occasionally you are presented with somebody who makes a decision and you, as a clinician, have to follow that through, and then they make a different decision and you have to follow that through. There is a logical position which I think has to be incorporated in the legislation which one that deals with that fluctuation of capacity. You have to have a plan of care as a clinician for an individual whose capacity fluctuates and that is a subtly different way of conceptualising their clinical problem. “Do I let this person walk down the street today and do I let this person walk down the street tomorrow?” You have to make a clinical decision as a clinician about what to do in both circumstances, and the decision as a whole has to cope with the fluctuation as a whole.

Q307 Baroness Knight of Collingtree: Thank you, Dr Kinderman, that was what I wanted to bring out. Does the Bill actually cover that variation that you have to deal with in the general rules?

Dr Kinderman: Yes, broadly. One of the issues it relates to is the issue of general authority. If the Bill were worded in such a way that preventing somebody from wandering were covered by general authority but their capacity as to whether it is dangerous to walk the streets or not was to fluctuate, what you would actually have to do is make a decision about whether a wider clinical decision was necessary on how to deal with their wandering and fluctuating capacity, and that would be the issue at question. One of the things which hopefully we will come on to in a minute is that such a decision might be covered by general authority, or restrictions on that person’s liberty might be such that you would need to do something a little more unusual and you would need more authority to deal with that.

Q308 Lord Rix: If you take it further and look at people who have a permanent limited mental capacity, not a fluctuating one, would you think it possible, and how would you make it possible, for them to make advance decisions, say, to refuse treatment? Do you think this could be written into the Bill?

Dr Kinderman: Yes, absolutely it can be written into the Bill, and I think the Bill as it stands—

Q309 Lord Rix: You think it is adequate?

Dr Kinderman: I think it needs to be followed up with a robust code of practice but the general principle, does this individual at this time in consultation with this responsible clinician understand the issues and the way they have been laid out, whether or not they have made a decision, the Bill allows for that and that is good.

Lord Rix: Good.

Q310 Mr Burstow: General authority, which we have been talking about for some while. I have a couple of questions but, just to make sure I understand the discussions so far around the two different Bills, can I ask this? You have described the two parallel systems of proxy decision making effectively, who decides which set of proxy decision making actually applies?

Dr Kinderman: There is not a Mental Incapacity Act at the moment.

Q311 Mr Burstow: Assume there is, who would then decide?

Dr Zigmond: I think that is one of the difficulties which we will be faced with. There are certain areas where it would be clear, an obvious one being that both the current Mental Health Act and the proposed one do not require any lack of capacity. So if people have capacity and for some reason you have to go down the road of compulsion, then it will be the Mental Health Act.

Q312 Mr Burstow: But it is unclear?

Dr Zigmond: For an incapacitated patient it would be very difficult. At the moment of course with the current Bill they need to be in hospital, and that may make a difference, whereas if we had a Mental Health Act which does not require admission to hospital, does not require in-patient status, it would become even more difficult. But, as I say, one of our fears is that it could lead to some of the provisions in this Bill being overridden.

Q313 Mr Burstow: I wanted to get that out because it is something we have to deal with. Can I ask on the question of general authority, the evidence from the British Psychological Society in a way puts forward the argument there is a need for a further element, another category, of proxy decision making, the idea that where you get to a certain intensity of activity or treatment or whatever that would then require registration with the public guardian. But that still leaves a whole host of issues which might fall within the general authority. Do you feel the general

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authority is a defensible idea which should stay in the Bill and how can we draw the boundaries on it once we exclude a whole range of things which should be referred down the registration path?

Dr Herbert: I think we have a general consensus that there is a huge amount of decision making which could usefully come under general authority which at present is happening anyway but has no clear framework. So many day to day care decisions are happening without a clear legal status and general authority would allow a vast chunk of those decisions to be made, whether in the best interests or that restriction would happen, but there is a threshold beyond which the seriousness of the decision and the nature of the decision would step in and say, "We just cannot work on best interests, we have to stand back and look at this." What we are saying is that that is not a one-off decision which is suitable for all cases, but sometimes it becomes a very straightforward, "Okay, we need to log the fact it has moved to a different level" and you do not need to do much more in terms of assessment because it is clear what the issues are. However, there are some small number of complex cases where you need a more detailed assessment and those are the things which are not specified in the Bill and probably should be in the code of practice but you need something which takes you through those levels in a systematic way.

Q314 Mr Burstow: What would be the test you would be applying which would enable you to make that judgment which should be in those codes of practice to ensure everyone adopts a similar approach?

Dr Dooley: I think there are a number of factors within that. I do not think we can specify the facts but a code of practice will be quite important to operationalise those. You have the severity of the decision; you have the person requesting the withdrawal of life-maintaining health care and matters like that. You also have the complexity of the situation, and I practice with older people where you may have disputes with carers, where a family member wants one thing and another member another and so on, so there is an area of complexity there. There are certain decisions which by necessity are high profile, and you have mentioned the one in the papers recently where in a sense to protect the people involved you need a formal decision making process and a monitoring of that.

Dr Zigmond: There are some areas where one would go towards registration but for many one would still want to have some system of notification. One of the difficulties it seems to us is that if there is no notification to a central body, how can anybody know these people exist and are being subject to something, so therefore any inspectorate just goes by the wayside. So we need notification. Secondly, when we met with the BPS and discussed this we decided there were some things which would need very clear thought when going into the codes of practice and it became clear through the discussion that one sees things from different sides depending

on what one is used to practising. For example, one of the things on the BPS list at the top is severe life-saving treatment. That may be okay if it can be done in the cold light of day but if somebody comes unconscious into casualty, you would not want to have to go through a system of registration before the doctors could intervene.

Dr Ehler: The other issue is that at the moment it is either/or, it is general authority or going to the courts. I think going to the courts can be very daunting for some people and apart from that it is also very costly, I would imagine. Earlier in the discussion there was reference to a continuum of factors and I think therefore there needs to be some sort of plan.

Q315 Mr Burstow: That is helpful. It does seem to me, Chairman, that is what this is suggesting, there is always another tier of proxy decision making being suggested. Can I come on to another question regarding general authority again? Several witnesses have talked about the issue of the use of restraint in certain circumstances, or have alluded to restraint being used or suggested there might be circumstances in which restraint might be appropriate for a person who lacks capacity. Is there not a certain situation where the use of the general authority could become a defence in the courts for what many would regard as an inappropriate use of restraint?

Dr Zigmond: Yes.

Q316 Mr Burstow: My final question is on the question of abuse more generally. Does there need to be a specific duty, and, if so, is it on the local authority or some other agency, to investigate allegations of abuse and also to be in a position, picking up on a point already made, to be aware there are people who are potentially being covered by this general authority?

Dr Zigmond: We think the important issue is expertise and availability. In Scotland it comes under the Mental Welfare Commission. Whether it should be a separate body or whether it should come under an expanded Mental Health Act, whether it should come under an expanded CHI system, whether it should be the local authority, we certainly didn't feel we should comment on it. The important bit is the expertise and availability.

Q317 Mr Burstow: Are you aware that local authorities already have a responsibility under "No Secrets Guidance" to develop adult protection?

Dr Zigmond: Yes.

Q318 Mr Burstow: Would not a statutory duty help reinforce that framework?

Dr Herbert: We have discussed that, and local authorities do already investigate individual cases. We feel that is not sufficiently robust as it stands at present and what you have is a case-by-case case law build-up in local areas. What we are arguing for is that there should be more national recognition of these issues so you do not have to start each time

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discussing issues of capacity. At present they operate in a vacuum. The other point on your question of general authority, what happens if there is a question of abuse, and what we are arguing for is as soon as there is a question mark about general authority and you are raising that challenge, that is when you start to say there should be an assessing of performance of some kind, which then opens up the opportunity for anybody who has a conflict with it which has not been solved by normal clinical case discussions, to have a way of taking it forward which is not immediately going to court but assessing it in a more balanced way and trying to take it forward in that way.

Dr Kinderman: You mentioned restraint, but wandering is a better example. At the moment because there is not a system of formal registration of these sorts of decisions with somebody like a public guardian, we do not know how many clinicians regard it as part of the normal clinical practice to restrict people's activity and their wandering behaviour. One of the benefits of a formal system of registering that is you know that and you may well find that people are waiting until it is an impacting decision on somebody's life before they actually decide they need to invoke the law. By having a system of registering these decisions, you would be monitoring it over the years and could find out how to respond.

Chairman: Before we move on to advance decisions, I want to be clear about the assessment of capacity.

Q319 Mrs Humble: Can I ask you the same question I asked our earlier witnesses which is vital because it underpins the whole Bill, which is that process of assessment of capacity. Who should do it? How should it be done? Especially with regard to those people who do not consent to being assessed. Do you think it should be on the face of the Bill or should it be in regulations?

Dr Kinderman: We think on balance it should probably be in the regulations. One of the reasons for that is that it is actually very complex. It is the duty of every doctor and probably every psychologist to have some awareness as they are treating a person of that patient's capacity to understand the decisions. That is just a general duty. It is also the case that the vast bulk of the decisions we are talking about which are covered by the Incapacity Act generally will be done under some general authority, it is a standard part of care. The decision as to whether you have to make a formal assessment of the person's capacity, decide they have capacity and decide to act under general authority, decide to make a formal assessment of capacity as part of your normal clinical practice, register the patient as an incapacitated patient and move on and treat them, whether you call in another professional or a more senior colleague, there is a gradation to these things and it should be part of the normal clinical practice of professionals to do that regularly. So the guidance is you should always have a view of capacity, you should assess it within your own

competence and call in specialist help to assess the more difficult areas when the decisions are more severe.

Q320 Mrs Humble: Is it satisfactory to have it done in that fairly vague way, of somebody reaching judgment through conversations with their patients, or should there be specific steps laid down, if not on the face of the Bill then in a code of practice, that you ought to be ticking off? If the individual is not co-operating, how can they go through that check list?

Dr Kinderman: I am sorry if you misunderstood. Yes, there should certainly be very clear guidelines about how it should happen and that should be regulated on the face of the Bill. There are two obvious things to say. The first is about the registration of people as competent authorities in this matter. One of the things the British Psychological Society would welcome would be some brief mention of approving certain people as registered practitioners, in the same way as is done under the Mental Health Act, when people are Section 12-approved because they have a specific competence in that area. That is one thing, are you or are you not capable of making these sort of assessments? The other thing is having guidelines laid down in a code of practice, which is referred to in the Bill, but which is flexible and hierarchical. We would certainly welcome strong guidelines but it is a hierarchical thing. You do not behave and then assess capacity and behaviour differently, you are always assessing capacity and always using clinical judgments to decide on this.

Professor Murphy: I would like to endorse that and say that for many situations assessing capacity is not that difficult and with a set of guided questions a general practitioner could certainly do it without any difficulty and a lawyer could certainly do it without any difficulty in lots of cases. We are only proposing it should go to a psychologist with expertise in that area where it is a very complicated decision and where you might need more advanced knowledge.

Q321 Mrs Humble: So you would expect different professionals to be making decisions on the particular issue on which the competence is being assessed? So, for example, a lawyer could make a decision if you are talking about somebody's competence to make a financial decision. They may be competent to make certain decisions but not necessarily the particular decision that has arisen, so are you saying it would only be in very complex cases it would go to somebody who would be registered on your list? Who would decide that that individual is a complex case and it should go that step further?

Professor Murphy: To answer the first part of your question, yes, that is what we are saying. I think it would be very easy to set out a framework that lawyers could use and GPs could use although it would have training requirements.

Dr Dooley: In some respects something similar is happening at the moment because if you take an elderly person in a medical setting in an in-patient

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ward who is behaving irrationally and perhaps not consenting to treatment, the first question would be, why is that happening? They might call in a psychiatrist to do an assessment about their capacity, that psychiatrist might then call in a speech and language therapist if that person has a communications difficulty, they might call in a clinical psychologist if they had reasonable memory difficulties. So in a way this is a mirror of that. It is a cyclical system. As we develop our specialist assessment we can then feed back to the more generic services the different aspects which allow us to assess it and that will inform their practice.

Dr Zigmond: Can I take it further in two respects? I agree with everything that has been said. If one looks at the current Mental Health Act, Section 57, that clearly gives to non-medical people who are members of the Mental Health Act Commission from any discipline, including lay people, the duty to assess whether in certain circumstances patients have capacity and are consenting in relation to surgery for a mental disorder. I do not think we should go down the route of saying that any particular group of people do not have skills in that area because with further training and within a regulatory framework we could include a wide variety of people. The second thing is, these are supposed to be situation-specific decisions relating to capacity. Let me give you an example. Suppose I was asked as a psychiatrist to assess if somebody was capable of making a decision as to whether they should have a hemi-colectomy, I would not have a clue. I do not know what is involved, how could I assess what the patient understood about what was necessary, about the pros and cons, about the adverse effects, the benefits and so on. So it would have to be, in those circumstances, a surgeon who knew what he was going to do, or she was going to do, who knew the sorts of information which the patient would require to make a decision and then be able to assess whether or not the patient was able to understand. It may be the patient could not do that by himself or herself and it would require two people or more. So the notion that somehow you can have an individual or a class of individual who can assess capacity I think is wrong. It is much more specific, just as whether the patient has a lapsed capacity is specific, so the people who would be involved in making that assessment at that time for that individual relating to that issue would have to be specific.

Q322 Mrs Humble: Accepting all of that, how does that lead into your earlier statement about having a registered group to deal with the more difficult cases?

Dr Kinderman: That was exactly what I was going to say. Here is an example, if my colleague over there were to arrest me and charge me with an offence, he would ask me if I understood the charges he was putting to me, and he would be making some sort of judgment within the bounds of his competence about my capacity. You would expect him to do that and that would be okay. If he had some doubts, he could call Tony to assess my capacity. What we are

saying for the purposes of this registration, what you should do as health care professionals is work within the bounds of your competence, judge patients' capacity, if you think they are incapacitated about a particular issue then you would operate under general authority. If you thought they were incapacitated and the issue was of a nature to warrant registration, there should be some people who are listed with the Court of Public Protection, or whatever it is, who have specific competence to rule on the more difficult issues. In the same way that the police officer can work out whether I appear to understand what he is charging me with, if I do not appear to understand, they should call in the police liaison doctor to assess me properly because that is the person capable of doing it. He assesses capacity, if he cannot, he calls on a colleague who does it in a more sophisticated fashion.

Mrs Humble: That is very helpful.

Q323 Chairman: It would be interesting to watch the process of a psychiatrist assessing a psychologist!

Dr Zigmond: There are limits!

Q324 Lord Rix: I come back to advance decisions. Should the Bill stipulate that advance decisions to refuse treatment should be made in writing after full consultation with the family? Would you consider it desirable for such decisions to be witnessed by a competent professional known to you, such as your GP or your lawyer, if you have one? If I can add a second part to that question which I was unable to ask your predecessors here, the BMA, if you have advance refusals already down and witnessed and fully documented, does this lessen your statements of wishes about, say, where you are going to be living in your extreme old age or the sort of health care which you will receive? Does the advance decision to refuse treatment always take precedence over an advance statement of wishes?

Dr Ehlert: It is a very complex question but I will try to answer it in parts. First of all, I think it is about looking at evidence, and certainly if you have not got something in writing how do you actually prove evidence that advance decision making has been made. I would say, yes, evidence in writing needs to be made or, for example, if the person cannot write things down to have some sort of evidence in writing. Should it be witnessed by a doctor or lawyer, the issue is that some people may not want to go to a doctor or a lawyer and therefore perhaps one should consider having two witnesses who were not professionals.

Q325 Lord Rix: Indeed.

Dr Ehlert: The other issue is that perhaps one should also consider that if one were to incorporate having two witnesses who were not professionals, then you would have to look at ensuring these people would not be benefiting by the person's death.

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Q326 Lord Rix: Of course.

Dr Ehlert: The other issue is of course cost. As soon as you start getting professionals involved there is a high cost. The other issue is that perhaps one should consider within a code of practice having a model living will or advance decision directive in order to set standards. Of course one could thereby take into account advances in medical treatment, actually ensuring that the person is able to renege on their original decision if necessary depending on the issue at stake in defining incapacity.

Q327 Lord Rix: What about advance statements of wishes? Are they lessened by the advance decision making?

Dr Zigmond: Could I come back to that? Could I first of all add that one of the interesting issues here is that Clause 24 is very detailed and the circumstances in which advance statements will not apply are very complex. We do not think it should have to go to a professional, it is expensive and why should you, but of course it is a bit like a will, the risks of getting it wrong and therefore your wishes not being followed are greater perhaps if you have not taken advice. I think that is as far as one could go. On the second point, clearly if there is any statement that is currently made by a capacitous individual, it should override a previous statement by the capacitous individual. So while they are able to make it, then I think it is very important. If I could give an example, it might illustrate some thoughts on this. I was at one of the conferences recently and a remarkable gentleman with Alzheimer's Disease was talking about this and said he had all his life hated to have a bath. He assured us he was very clean but he liked to shower and he wanted his wife to be able to convey that at such time as he was no longer able to. It occurred to me that at that stage it may be he would prefer a bath, he does not know what he would want then. I suspect he would have to be really quite severely damaged before he was unable to make that decision at that time, and the thought of him trying to climb in a bath and someone pulling him out saying, "No, your wife says you are not to have a bath", seems a little harsh. So I think the issue is one of constantly deciding for this issue, the seriousness of this issue, is that person still able to make a decision and, if they are, then that is what must count.

Q328 Lord Rix: I have drafted something fairly recently based on a living will, which seemed to be fairly wide in its implications but actually quite specific. It refers to "life-threatening physical illnesses from which there is no reasonable expectation of my recovery or of severe and permanent impairment of all my intellectual faculties together with a physical need for life-saving treatment" and it then goes on to say what you want to do. I would have thought that was not being unreasonable. You are not saying to somebody, "Kill me, please, automatically", you are saying, "When those conditions are reached I request all treatment necessary to maintain comfort and dignity

and relieve pain even if this is likely to shorten my life . . ." and obviously I am thinking of morphine, ". . . and to refuse treatment aimed at prolonging or artificially sustaining my life." Would you not think that was reasonable?

Dr Zigmond: I think it is excellent. In order to be slightly devil's advocate though, supposing you have a condition which is a terminal condition and something happens which causes you pain and the only way I can treat that is not by shortening your life but by extending it.

Q329 Lord Rix: Like putting me on chemotherapy?

Dr Zigmond: In order to deal with the pain, not in order to extend your life. Would your wording cover that?

Q330 Lord Rix: Yes, I think it would.

Dr Zigmond: I merely give that example to show just how difficult it is to be precise.

Q331 Lord Rix: Indeed.

Dr Zigmond: The principle, absolutely.

Chairman: As we have not got the wording in front of us, we should perhaps move on.

Q332 Mrs Browning: For those people who have a known condition which results in fluctuating capacity throughout their life, would you as professionals feel that during those times when they clearly have capacity you would feel it incumbent upon you to encourage them to take those advance decisions? Would you be pro-active in doing that?

Dr Zigmond: Yes.

Dr Kinderman: Yes.

Dr Dooley: Yes.

Dr Ehlert: One of the pointers in relation to the evidence is about registration. At the moment it would be quite difficult to actually find out whether anybody has made a living will or advance directive in relation to their health care, so therefore one should consider some sort of registration process which is accessible in order to find out whether those decisions have been made.

Q333 Baroness Knight of Collingtree: Really this is crossing Ts and dotting Is and following on something which Dr Zigmond and Dr Kinderman said. Do you think it would be good if the draft Bill actually put a specific duty on doctors and other professionals to ensure that an advance decision to refuse treatment is not leading to unintended harm and some kind of mechanism whereby unintentionally harmful decisions could be avoided or set aside?

Dr Herbert: That is covered by Clause 24, is it not?

Dr Kinderman: We had a discussion about this when we saw the question and we came to the conclusion that that is covered by the issue of what constitutes the invalid decision, Clause 24. I have not got it in front of me but it says something along the lines that if that decision was made on advice but there was

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something which was not foreseen by the person, and if it is unintended it was not foreseen. We thought it was probably covered by Clause 24.

Dr Zigmond: Could I add, please do not ever put on me a requirement to ensure anything. You can ask me to try and ensure, or do my best to ensure, but how I can ever ensure for certain anything, I do not know.

Q334 Baroness Knight of Collingtree: I was not so much asking you to ensure—and how I would ever ask a psychologist to ensure anything, I do not know—I was merely hoping possibly the Bill might be able to.

Dr Kinderman: Just to clarify, Clause 24 refers to circumstances which were not anticipated, and if you are talking about “unintended” that would seem to cover that.

Q335 Baroness Fookes: Basic care: do you believe that the Bill should exclude basic care from its procedures and its mechanisms or not?

Dr Herbert: No, the strength of the Bill is that it does include them under general authority because those are the sort of things which we are saying are left out.

Baroness Fookes: So you are all agreed.

Q336 Baroness McIntosh of Hudnall: This is about the duties of people in possession of lasting power of attorney. Is it your view that there are sufficient safeguards in this Bill to ensure people carried out their responsibilities effectively? Specifically, do you think that the Bill will be improved by the list of, as it were, specific provisions of duty of care being placed on people who have lasting power of attorney and a list appended of what that implies?

Dr Kinderman: In the absence of anybody else saying yes, the answer is yes.

Q337 Baroness McIntosh of Hudnall: Commendably brief.

Dr Kinderman: One of the benefits of strengthening it—and this includes cost because there is a secretariat involved—and having these things, including registration of patients as being incapacitated with the public guardian, is you have staff to do research on that and they can look to see how many of them are there, what they have written, how many would be invalid if you were to look at them as a lawyer, and you can only start to do that if you move down that path.

Q338 Baroness McIntosh of Hudnall: Can I reframe the question because I want to make sure I have understood your answer and that indeed you understood my question. It has been put to us that the Bill is deficient in that it does not specifically impose a duty of care on those who have lasting power of attorney granted to them. Do you think the Bill would be improved by that duty of care being made explicit and binding?

Dr Ehlert: Basically some sort of mechanism to ensure further safeguards potentially needs to be incorporated in a code of practice. For example,

actually ensuring that anyone with lasting power of attorney is looking after the welfare of the person concerned like in terms of financial aspects. For example, one could look at having some sort of audit on an annual basis of the accounts, otherwise anyone could end up doing anything. On the other hand, there are at the moment quite significant restrictions in relation to power of attorney where the person has to go to court to give out gifts and things like that which the person might have normally done anyway, so therefore one could look to see whether the person has got, for example, a will which could be drawn on in order to look at issues of disputing gifts and things like that. I do not know if that makes any sense.

Dr Zigmond: Could I give an example of a difficulty?

You have an elderly person who is suffering from a degree of dementia, which is sufficient to lose capacity in relation to where he or she should live. They are in hospital and the time has come for discharge. They have spent their whole life talking about—and they have not made an advance statement—the importance to them of staying in their home with all necessary support but the problem is they do fall over. One of the children, who is extremely caring and extremely fond of them, says, “They would be safer in a nursing home, so we want this person in a nursing home.” You know the patient actually wanted to go home and you think as the doctor with the necessary support they could be maintained there. That is not an uncommon scenario and it is a very difficult one. They have given the authority to their child, quite rightly, that is what they wanted to do, and I think that anything that reminds the person with lasting power of attorney of the fact they have duties to consider that list, including the discernible wishes of the patient, would be very helpful. I do not know if that answers your question.

Q339 Mrs Browning: Could I add another twist to that which is familiar to many of us, and that is the elderly person who in their 60s and early 70s says, “If anything happens to me, don’t worry about putting me in a home”, but when they get to their 80s and they are falling over, they say, “No, no, no, I’m not going in there!” That is also a very difficult situation and yet they have expressly, when they certainly had capacity, expressed a different view.

Dr Zigmond: Yes.

Dr Herbert: There is a need for us all to change our minds sometimes.

Q340 Chairman: But they have the capacity at that time to say no.

Dr Herbert: I think we have to be quite clear that lasting power of attorney does not have to give you total rights over that individual, it might give you rights to make decisions in certain areas and that might be one of the safeguards you ought to have.

Chairman: I think we have reached the point now where we have been going for 2½ hours but there are two areas we have not reached, and those are lessons from other jurisdictions, excluding Scotland which

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we have spoken about. If you have any views on that, do write to us, and also if you would write to us about resources. Can I thank you all for an extremely helpful session. If there are any other

points you wish to make about things which should have been asked or things you would like to expand on, we would be glad to receive them. Thank you very much indeed.

9. Supplementary memorandum from the British Psychological Society (MIB 1205)

Ms Karen Ehlert	Honorary secretary, Division of Clinical Psychology, BPS
Dr Camilla Herbert	Chair, Division of Neuropsychology, BPS
Professor Glynis Murphy	Fellow, BPS
Dr Peter Kinderman	Chair, Division of Clinical Psychology, BPS
Dr Catherine Dooley	BPS

PRELIMINARY QUESTIONS

1. *The Draft Bill would put into statute a number of principles already encompassed by common law. It would also establish several new systems relating to substitute decision-making. In your view, does the Draft Bill go far enough to clarify and improve the decision-making process for professionals, families, carers and those who are unable to make decisions for themselves?*

The BPS welcomes the Bill and, in general, welcomes its structures, clarity of language, and content. We have reservations, detailed below, but we think it is a positive move forward.

2. *In your view, does the Draft Bill place sufficient emphasis on the need to facilitate the making and communication of decisions by people with incapacity?*

The BPS supports the need to emphasise appropriate and alternative modes of communication, for example, use of interpreters and technological aids, so that the views and opinions of the individual with impaired communication can be made known to professionals, carers and advocates, irrespective of the communication method. Alternative and assisted means of communication are not adequately covered in the draft Bill. However, this can be addressed in two ways. First, by incorporating a Statement of Principles on the face of the bill (similar to the Incapacity Act in Scotland 2000) which would directly address the issue of an autonomous decision being made possible by appropriate facilitation. Secondly, the BPS supports the recommendation of the Making Decisions Alliance, that Government Departments develop a Code of Practice, involving, and incorporating the views of the relevant professional and other representative bodies. This recommendation is made in order to ensure that those capable of making decisions are facilitated in doing so; that the rights of the incapacitated person are protected; and that proxy decision makers are aware of their obligations and the scope and limits of their power.

3. *In your view, are the boundaries and overlap between the Mental Health Act 1983 and the Draft Bill sufficiently clear and workable? Is this likely to change if the proposals for a new Mental Health Act are enacted?*

The BPS accepts that there will be overlap between the two statutes but recommends that there is a need for compatibility. The BPS believes that both Bills should address the issue of people who are unable to make valid decisions. The emphasis of the Mental Incapacity Bill is placed on the needs of people who cannot make decisions for themselves, many of whom do not have mental health problems and would not see themselves as part of such a framework. Their needs include the making of decisions about legal, social, financial, and health care issues. In contrast, the Mental Health Bill addresses the needs of people whose decisions may be biased by mental disorder, and is primarily concerned with the decision to accept treatment for mental disorder. Therefore, the BPS suggests that Section 27 which addresses specific areas of overlap should be amended. Clarity is needed concerning:

- (a) individuals who do not have a defined mental illness but where a degree of compulsion or constraint may be required. This may include individuals who are likely to wander in a confused state where a secure and protective facility may be helpful; and
- (b) individuals who are unable to make valid decisions for themselves under the definitions of the Mental Incapacity Act who also have mental health problems as defined by the Mental Health Act. The BPS welcomes the definition of capacity used in the Mental Incapacity Bill and recommends that the Draft Mental Health Act should include a criterion of "impaired judgement".

Finally the BPS questions whether the title of the bill adds to the potential confusion with the Draft Mental Health Act, and would support the title “Incapacity Act” (similar to the Scottish experience) as a useful way forward.

4. *The BPS advocates the inclusion of a statement of principles at the start of the Bill, similar to that included in the Draft Mental Health Bill. Does the RCP agree?*

The oral evidence would suggest that the RCP does support this.

ASSESSMENT OF CAPACITY

5. *Should the Bill specify how or by whom an assessment of capacity should be made, in respect of individuals who do not consent to be assessed? Or should this be left to the Code of Practice?*

The BPS believes that there should be a hierarchy of statutory response and a hierarchy of assessment. For many people the General Powers of the Incapacity Bill could be used to facilitate and legitimise basic care. All healthcare workers can and do assess capacity as part of their work, but at present such assessments are informal and idiosyncratic. This Bill would make this more systematic and auditable. The BPS believes that more serious decisions should be preceded by a process of Registration of the patient with the Public Guardian. We recommend that this should be attested to by a Registered Practitioner and that this requirement should be included in the Bill. Such registration should be accompanied by an appropriate assessment by an appropriate professional. In some cases this will include psychologists or other health care professionals such as speech and language therapists. However the level and type of assessment required will vary according to the complexity of the decision being taken, and this would be best described within the Code of Practice. The Draft Bill unnecessarily excludes relevant health care practitioners from providing an opinion at this level due to the use of the term “medical”.

GENERAL AUTHORITY

6. *Where should the limits of the General Authority be drawn in relation to medical treatment?*

The BPS believes that most care would be conducted under General Authority, but that if there was dispute or a serious intervention was being considered, then Registration would be necessary to ensure that an appropriate assessment of capacity had been carried out.

7. *The BPS propose that in certain circumstances, use of the General Authority should be controlled by a system requiring formal registration of the incapacitated individual with the Public Guardian. As far as clinicians are concerned, what advantages would a formal registration system have over the current proposals for the General Authority?*

A formal system of Registration would provide a safeguard for patients and clinicians by ensuring that important decisions are open to scrutiny. For the clinician such a system would offer protection from claims of clinical negligence and inappropriate behaviour. In addition, it provides a mechanism for recording evidence along with the rationale for proxy decision-making. Under the existing proposals for General Authority there is no system for monitoring or auditing proxy decision making. The BPS believes that most registrations would be uncontroversial, for example, the enacting of a lasting power of attorney for an adult with dementia, and would not incur substantial costs. However, closer scrutiny will need to be provided for people with acquired brain injury and learning disabilities. Therefore, a Code of Practice should provide guidance as to when a straightforward registration is insufficient and also provide recommendations regarding further assessments, and by whom these should be undertaken. The BPS does not see Registration as necessarily restrictive of the individual’s ability to make decisions in areas not covered by registration.

8. *Do you consider that the admission of an assenting incapacitated person to hospital by a doctor acting under the General Authority resolves the “Bournewood gap” and provides sufficient protection for both the doctor and the patient?*

The BPS believes that the Mental Incapacity Bill will address the Bournewood Gap.

9. *Should Local Authorities be given duties to investigate possible abuse taking place under the general authority? Would this alternative approach help address any concerns you might have about the exploitation of vulnerable people?*

The BPS believes that, whilst it is not inappropriate for the Local Authority to have investigatory powers (as they do already), the proper oversight body for the Mental Incapacity Act would be the Mental Health Act Commission or its successor body. However, in keeping with a hierarchy of decision-making authority, the BPS concurs that disputes are addressed quickly. Therefore, informal dispute resolution services should be set up. Public Services in general should have a legal duty to investigate incidences of actual or potential abuse, neglect and exploitation. This recommendation is in keeping with the Decision Making Alliance.

ADVANCE DECISIONS TO REFUSE TREATMENT

10. *Should the Bill stipulate that advance decisions be made in writing? If so, would it be desirable and practicable to include a provision that they should be witnessed by a competent professional such as a doctor or lawyer?*

The BPS's view is that whilst an adult retains capacity and is able to make their views known the issue of written or oral statements does not arise. The Mental Incapacity Bill has to address the issue of whether such statements should be respected once the capacity to revoke them or to change them is lost. The validity of advance directives are already addressed in Common Law. However, the BPS recognises that individuals do change their minds and would support the statement under clause 24(4c) which recognises "unforeseen circumstances" that might have influenced one if one had known of them, such as advances in medical treatment, associated with an improvement in quality of life, not anticipated at the time of the advance statement.

The advantages of a written statement or a statement evidenced in writing is that it provides evidence as to a persons values and wishes, it also acknowledges the importance of self determination with regard to cessation of treatment. A formal process of registration will ensure the greater likelihood of the information being available when required, and would also demonstrate that the individual had had an opportunity to consider the issue in some depth. It is the BPS's view therefore that written statements, or statements evidenced in writing are important.

The acknowledgement of advance decision-making in the Bill will provide greater clarity in the provision of health care, for those who become incapacitated, but who have made their wishes known in advance. It will also assist in providing protection for professionals and follow advance decision-making documents. However, advance decision making needs to be backed up by a Code of Practice that covers issues such as the drafting and implementation of advance directives.

The BPS is concerned that additional costs and delay should not influence the equity of provision of advance statements. It is acknowledged that individuals who are competent to make advance decisions may not wish to engage a doctor or lawyer in the process of witnessing the written statement, although they may wish to obtain relevant information from them. Given that the document reflects personal wishes, consideration should be given to the document being witnessed by two people who will not benefit from the death of the individual drawing up the document. This can be addressed in a Code of Practice.

11. *Should the Draft Bill specify a duty on doctors and other professionals to ensure that an advance decision is not leading to unintended harm, and include a mechanism whereby unintentionally harmful decisions could be set aside?*

This is addressed under clause 24(4c) and can be further clarified through a Code of Practice.

BASIC CARE

12. *Should the Bill exclude "basic care" from its procedures and mechanisms? If so how should "basic care" be defined?*

The BPS strongly supports the inclusion of basic care as part of General Authority. The BPS further believes that, whilst this should cover most actions, there will be actions over and above basic care which should be covered by a process of Registration. We do not have specific advice on definitions of "basic care".

LASTING POWERS OF ATTORNEY (LPAs)

13. *In your view, are there sufficient safeguards in the Draft Bill against donees of lasting powers of attorney failing to carry out their responsibilities properly?*

The BPS believes that the Bill should include specific provisions to ensure that recipients of donee powers are placed under an obligation to fulfil these duties properly and that a mechanism for monitoring donees is established, in order to ensure that individuals who are no longer competent to make decisions, are protected from exploitation, abuse and neglect.

MEDICAL RESEARCH

14. *Is it necessary for the Draft Bill to contain provisions regarding the involvement of incapacitated adults in research?*

Yes, see below.

15. *How might you balance the need for research to arrive at treatments for such disorders as Alzheimer's disease against the risk of exploitation and abuse?*

The BPS believes that such balance is the province of Local Research Ethics Committees and values their work, see below.

16. *To what extent do you consider that the present role of ethics committees are a sufficient protection for incapacitated or potentially incapacitated people from research that might be inappropriate and/or exploitative?*

The BPS supports the existing role played by ethics committees, but feels that decision-making will be enhanced by greater clarity provided by the Mental Incapacity Bill—see below. Furthermore, it is important that there is consistency in the standards adhered to by the various ethics committees.

17. *Is there a need for a formal "substitute decision-making" procedure whenever an incapacitated person is to be involved in research?*

The BPS believes that the Mental Incapacity Bill should include specific provision for research. We believe that this should address specifically the role of Local Research Ethics Committees (LRECs). We believe that LRECs should be given a formal legislative framework for their rulings in this area. There will be occasions where the research would involve interviewing a relative or carer and would not present unnecessary risk or exploitation of the individual concerned. However we believe that the Mental Incapacity Bill should specifically require LRECs to insist that individual proxy consent be obtained for research participation by incapacitated persons.

LESSONS FROM THE OTHER JURISDICTIONS

18. *Would the witnesses like to draw the Committee's attention to any aspects of similar legislation in other jurisdictions which they feel are instructive to consideration of the Draft Bill?*

This is outside the area of our expertise.

RESOURCES

19. *Written evidence received by the Committee states that there will be a need for a "huge investment in training" and "a substantial research programme" to support the implementation of the Bill. Roughly what sort of sums of money do you think would be involved in England and Wales?*

The reference to "huge" investment of financial resources originated in the submission by the Scottish BPS. We apologise for any misinterpretation by the Committee, but we do believe that the provisions of the Bill will need to be properly resourced in order for the proposed legislation to actually provide the improvements that it promises and which we support.

We believe that the resources will be needed in three areas: staffing, training, and supporting/evaluating the implementation.

Staffing: We do not anticipate "huge" extra demands on staffing as a result of the Bill if it is clearly drafted and the Code of Practice is readily available. The Bill will codify existing good practice which already includes the demand for specialist assessments by psychologists. The BPS strongly supports the statutory recognition of assessments by psychologists, and we do anticipate that there will be an increase in the demand for our services within the health and social care fields. Planning for this, however, can be considered as part of the ongoing workforce planning discussions with the Department of Health.

Training: All registered practitioners will require a basic level of training in order to implement the proposals under the new legislation. This would necessarily include a range of medical practitioners such as GPs, psychiatrists and physicians, but might also include lawyers, psychologists or other health care professionals. More detailed specialist training would be required for professionals to be registered to provide specialist assessments. Although there would be a need for training in the legislation itself, many of the clinical skills required by clinical psychologists and neuropsychologists will be met through their doctoral and post doctoral qualifications and continuing professional development and would not be an additional cost. The target population for training of specialist psychologists would be in the order of several thousand initially, with a smaller number of new practitioners being added over subsequent years. Typical training costs range between £30 for a short didactic session to £500 for a longer workshop event.

Evaluation: The BPS strongly recommends that the workings of the Act be subjected to careful evaluation and research. Information will be needed as to how many people are meeting the criteria for Registration and for what types of decision, how often General and more Specific powers are being used, complaints etc. These evaluation and research procedures will have costs attached.

Finally, the BPS believes that the implementation of the Bill will need a secretariat to support it. There will need to be a register of approved professionals, and a system to log and manage the registration of patients, request specialist assessments and scrutinise the workings of the Act. There will be significant costs if the Bill is enacted properly, but the BPS believes that this is an important piece of legislation that will have a positive impact on those who have capacity to make decisions but have difficulty in communicating them, people who do not have the capacity to make decisions, their relatives, carers and professionals involved.

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10. Supplementary memorandum from Dr A S Zigmond (MIB 1219)

In relation to the two final questions I am sorry to say that the College can be of little assistance. We have no experience of equivalent legislation outside of Scotland.

We recognise that there will be additional costs in relation to the Bill although we have no means of quantifying them. Much of the Bill should clarify matters but not greatly alter practice from that which currently exists. The enhanced protections set out in the Bill will undoubtedly have costs attached but the College believes that they are of such fundamental importance that it should be considered "money well spent". As an aside might I add that this is very different from our view of what we think will be considerable workforce and financial costs in relation to the Draft Mental Health Bill.

Finally I must comment on the process. We were most pleased that you were able to attend the College dinner in Bournemouth and I am personally grateful for having had the opportunity to convey to you those matters which we thought were important for the Joint Committee to consider. I think it fair to say that I had very considerable qualms about giving evidence but the way we were questioned enabled all of us to give our opinions in an open and constructive way.

October 2003

Thursday 9 October 2003

Members present:

Carter, L. (Chairman)
Fookes, B.
Knight of Collingtree, B.
McIntosh of Hudnall, B.
Rix, L.

Mrs Angela Browning
Mr Paul Burstow
Jim Dowd
Mrs Joan Humble
Huw Irranca-Davies

11. Memorandum from Professor the Baroness Finlay of Llandaff (MIB 1186)

I am aware that your joint committee will shortly be considering the Mental Incapacity Bill.

As you may be aware, I have tabled an amendment to the Patients' Protection Bill, introduced By the Noble Baroness, Lady Knight. This amendment should hopefully be incorporated at third reading. It concerns incapacity and I hope it is compatible with the draft Mental Incapacity Bill.

I would be grateful if you could confirm to me that, in the event of the definitions being amended in the Mental Incapacity Bill, the wording would then also automatically amend the Patient's Protection Bill. This will be important to ensure we do not end up with more than one legal definition for clinicians. I am most grateful to you for your advice.

I would appreciate the opportunity to discuss with your committee the problems of incapacity in the seriously medically ill and particularly in the terminally ill patients. There may be issues around the workability, as you alluded to in the themes to the scope of enquiry on the Bill. I have particular concerns over legally binding advance directives in patients whose levels of competence rapidly fluctuate and are difficult to assess. I do hope I can be of assistance.

August 2003

Witness: Professor the Baroness Finlay of Llandaff, a Member of the House of Lords, examined.

Q341 Chairman: Can I thank you for attending? This session is open to the public and it is being recorded for broadcasting. There will be a verbatim transcript of the evidence which will be published in the report and you will be asked to check the text of the transcript for accuracy. We would ask for that to come back within seven days. If there is a division in the House of Lords, I will have to adjourn. There should be a note of the relevant interests of Members of the Committee on the table. Members of the departmental and Bill team are present as observers. If we are not able to reach any of the questions, we are happy for you to respond in writing or make any other points which arise from the evidence. We are not here to write a White Paper on mental incapacity; we are here to report on a Draft Bill and that is the reason why the questions are structured around the structure of the Bill. Would you like to introduce yourself?

Professor the Baroness Finlay of Llandaff: I am Baroness Finlay of Llandaff. I should declare I am a past chairman of the Association of Palliative Medicine in Great Britain and Ireland and I currently hold an honorary chair at the University of Wales College of Medicine in palliative medicine. I am a consultant physician in palliative medicine to the Velindre NHS Trust.

Q342 Chairman: Does the language which you propose in the amendment which you tabled to the Patients' Protection Bill significantly differ from the comparable text of the Draft Bill which we are considering?

Professor the Baroness Finlay of Llandaff: I am most grateful to the Committee for inviting me here. I rechecked the wording of the amendment and I had thought that we had used the wording as had been proposed in the draft. I am sorry if I have missed something. I had understood that we had used it because I had understood that therefore if the wording came in and was different the previous Patients' Protection Bill would simply be referred to and that change would supersede the wording in the Protection Bill. It was for that reason that we tried to be completely compatible. The only change in the wording relating to the narrow application in the Patients' Protection Bill from the wording in the Draft Mental Incapacity Bill is that the latter has broader wording in one line.

Q343 Chairman: What you appeared to do with the amendment to the Patients' Protection Bill was to lift the faults of the wording out of the draft Bill and put them into that one?

Professor the Baroness Finlay of Llandaff: Yes, that is correct, for the very important reason of compatibility and avoiding confusion.

Q344 Baroness Fookes: You will know that under the Draft Bill capacity is regarded as decision-specific. Are you affected in any way by patients who need palliative care whose capacity may fluctuate a little or a lot? Could you tell us about that?

Professor the Baroness Finlay of Llandaff: I have been very concerned because capacity fluctuates very rapidly in patients who are extremely ill and also because it can be very difficult to judge capacity. If I can give you two specific and very common instances, one is where patients have been anxious, which is understandable because they are facing dying, and where the benzodiazepine group of drugs such as Midazolam are used to remove the churning drive of anxiety without sedating the patients so they can still function but they are relieved in part of this desperate feeling of anxiety, butterflies and churning inside. With some of those patients, you can have a conversation and they appear to understand everything that is said and have recall. The following day they have no recall whatsoever of that conversation. It may have been a few hours later in some patients. Another situation which arises is where patients' calcium levels go up and that occurs in about ten per cent of all cancer patients. They become confused. That is a gradual onset and the onset is difficult to diagnose. They may appear to be arguing rationally but when their calcium has been brought down and is treated they then are behaving differently and they have no recall of that previous conversation or the direction that they were trying to give in expressing what they wanted. Also, they may completely change their mind which is a terribly important situation for the clinician. The difficulty is in judging whether they have capacity or not because at any one point in time the conversation appears to be logical and consequential. The issue of recall is impaired. Those are the two common situations. There are lots of other situations which arise, particularly with patients on steroids where the steroids may have created a very mild steroid psychosis which can be difficult to diagnose and just presents as emotional immobility. Again, their thinking and perception are distorted.

Q345 Baroness Fookes: How do staff cope with these difficulties which you have outlined very graphically?

Professor the Baroness Finlay of Llandaff: We cope with difficulty and with a fair degree of fear and dread, trying to ensure that the patients are given choices that they can cope with but being aware that the person in front of us, as they are presenting, and the person that they might present to us tomorrow or might have presented to us yesterday is different. If this is somebody who you have not known for many weeks, months or years, it can be difficult to know which of those presentations truly represents the person as they were previously. The other difficulty is that people change anyway as they go through their lives and their illnesses. The situation which somebody deemed to have been quite impossible to cope with, should it arise, when it arises, they cope amazingly with and have a different perception and interpretation of it. If I may illustrate that point very briefly with a clinical example, a lady I had said that the worst thing that could happen to her would be to have a spinal cord compression and be

paraplegic. She dreaded that more than anything else. Sadly, as happens all too often, the single thing that people dread the most is the thing that does happen. She developed a paraplegia. She did not respond to radiotherapy. She was devastated. I was devastated, having to tell her. Some weeks later, she said she never believed that life could be so rich and that she could find so much meaning in life and being confined to a wheelchair was relatively trivial compared to the total disaster that she had contemplated from that scenario. She said she was noticing the daffodils coming up in spring which she had never noticed before. She was able to receive care from her husband which perhaps her pride would not have let her do previously.

Q346 Baroness McIntosh of Hudnall: May I take you back to the point you were making about capacity that is caused to fluctuate by medical intervention? You describe a situation where the outcome of that intervention appears to be unpredictable. That is to say, somebody who is in one case is then given certain drugs; is then in another case but that case is not predictable. What I am hearing—and I would like you to correct me if I am wrong—is that you cannot predict the effect of that drug sufficiently to know whether person X in receipt of those drugs does or does not lack capacity. Is that the case?

Professor the Baroness Finlay of Llandaff: In essence, I would agree with you. The difficulty is that you can say that that is a predictable side effect, but you cannot predict in a person specific way. Steroids are a classic example. You know a steroid psychosis is a risk but you cannot look at somebody and say that they are particularly at low risk, although you might be able to say, based on past experience, they are particularly at high risk.

Q347 Baroness McIntosh of Hudnall: In the case of the drugs that you were describing that you would prescribe in the case of acute anxiety, the desired effect is the relief of anxiety?

Professor the Baroness Finlay of Llandaff: Yes.

Q348 Baroness McIntosh of Hudnall: The actual effect is some loss of capacity to understand?

Professor the Baroness Finlay of Llandaff: A secondary effect.

Q349 Baroness McIntosh of Hudnall: Secondary but it does not occur in all cases or it does occur in all cases but in varying degrees?

Professor the Baroness Finlay of Llandaff: I do not think anybody has systematically, carefully assessed the degree to which capacity is impaired using a battery of tests. There was some important work done I think in Canada where patients who were thought to be competent were repeatedly tested. The more that you tested them, the greater the deficit in capacity. The problem is that if you use a blunt test or assessment and not a sensitive assessment they may appear to have capacity. That is the catch for the clinician.

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Q350 Chairman: Do you know if in Canada they needed the consent of the people to take part in the research?

Professor the Baroness Finlay of Llandaff: You would always need consent to undertake any research.

Q351 Chairman: In Canada? Do you know that?

Professor the Baroness Finlay of Llandaff: Yes. I apologise to your Lordships. I tried to get the reference to this before coming today and I have a colleague in liaison psychiatry tracking it but he could not get back to me before I came today.

Q352 Mrs Browning: Is there very much difference between this particular patient you have described and, say, the elderly and confused before they reach the stage where a doctor has diagnosed dementia or Alzheimer's? If you look at that group, they too have their good days and bad days. They have short term memory loss and it is difficult to know when you have a conversation on a good day whether or not they will remember it the next day. Are they not all covered by this proposed legislation and would not the consequences be the same for a wider group than the one you are mentioning?

Professor the Baroness Finlay of Llandaff: I would agree with you that it would apply to anybody with mental illness.

Q353 Mrs Browning: Medicated or not?

Professor the Baroness Finlay of Llandaff: Medicated or not. It is not the drug; it is the disorder in their physiology from their illness. You would see people with a urinary tract infection become quite confused as a result of that infection without any drugs. The difficulty in patients who are terminally ill is that time is so short. They are already so ill and therefore so vulnerable that a decision you take may make the difference between them continuing to live or their life being foreshortened in a much more dramatic way than in some of the other patients. Patients with Alzheimer's quite often are physically remarkably strong, despite the mental impairment, but these patients are physically very severely impaired and often in a very fine biochemical balance. An example would be patients in renal failure who will feel absolutely terrible and may feel very clouded. In assessing their ability to take decisions you should always veer to the side that they are competent because it is astounding, if you take care to communicate with people, how much they are able to take decisions. It is a long, slow, complex process.

Q354 Lord Rix: Would you say that all people in need of palliative care—most or some or few—have changing capacity?

Professor the Baroness Finlay of Llandaff: No, I would not say "all" but I do not think this has been systematically researched across a population with advanced disease as their deaths are approaching. Until that is done in a really systematic way, I do

not think I could confidently give the proportion. The difficulty arises for a clinician particularly where the family are in dispute perhaps amongst themselves and also in dispute with the clinicians over a patient's wishes or over their ability to take a decision. That is sadly a not uncommon occurrence. Where a family's views differ and carers' views differ, it can be very difficult to know who really understands.

Q355 Huw Irranca-Davies: In your correspondence to the Committee, you raise one particular concern in respect of fluctuating levels of competence and it is in respect of the legally binding advance directives and what impact these will have. Could you expand on that and give some examples of the difficulties you see with those?

Professor the Baroness Finlay of Llandaff: Some of the concerns are whether this was truly their wish, made completely voluntarily, free of any influence. When they wrote their document, did they have a degree of depression that had not been assessed? Were they highly emotional at the time and therefore feeling in despair? A person who feels that they are a burden to others will have a much blacker view than a person who feels confident and secure that the others around them love them. Sadly, it is only too common for patients to feel when they become ill that they are a burden, either to their families or indeed to society, through deficits in care. I am concerned that that can influence their thinking. The other problems relate to when was it written and, although it was meant to be specific to a situation, it is relatively rare to really be able to envisage how you would feel if that situation arose. In the example I gave of the spinal cord compression, that lady had written an advance directive saying that she did not want any treatment to prolong her life prior to the spinal cord compression arising. When she developed a chest infection which was life threatening, I went and discussed with her whether she did want antibiotics. Some of my colleagues thought that that discussion with her could be deemed to be burdensome and interfering because they were saying that was her advance directive and that is what we have to stick with, but when I spoke to her again she said, "I want antibiotics this time. I think the next time I will not want them." It is a feature of people who are suddenly facing the reality of their dying that they could not preconceive how they would feel at the time. That is also a situation that one sees in people who are very seriously ill.

Q356 Baroness McIntosh of Hudnall: What you are describing there is somebody who does not lack mental capacity, a patient who, within the terms that we are discussing, is able to make a choice. Had that patient been in exactly that same condition physically but with the advance directive and without capacity to have the discussion with you which she did have, you with your colleagues

would have been obliged to follow her advance directive. What do you imagine you would have felt in that situation faced with that reality?

Professor the Baroness Finlay of Llandaff: When I went to renegotiate with her, she was on a lot of medication of different types. She was not medication free. There was even a question as to whether her capacity was impaired or not. In the principle of veering towards capacity being present rather than not present, for that decision to be taken, that influenced it. I would have felt quite uncomfortable because the advance directive was made in a situation and a scenario that was very different to the one that she found herself in because a lot of things had changed in the world around her. Her relationship with her husband had changed a lot through the course of her illness, so her perception of her role within that relationship was very different. She had gone from being a fiercely independent woman to being able to accept dependency far beyond the way that either she or her husband would have conceived previously. That is where I have a concern with the concept of personhood, whether the person in front of you now has changed so much from when they wrote the advance directive, because even ordinary life experiences change us.

Q357 Baroness McIntosh of Hudnall: The Bill provides for circumstances to change. It does not specifically provide for personhood to have changed. Do you believe that the language it uses does not cover that?

Professor the Baroness Finlay of Llandaff: My biggest concern is that the language does not specify voluntariness. If I am teaching about consent, one of the main principles is that it is voluntary and free of any type of coercion. I am concerned as to how you would know with an advance direction given to you that it was truly free of any coercion through emotional or social circumstances or whatever.

Q358 Chairman: Would that still apply if the advance directive had been legally witnessed by a doctor or a lawyer?

Professor the Baroness Finlay of Llandaff: With all due respect to lawyers, I am not sure that they are very good at assessing the subtlety of someone's emotional state and, with all due respect to my medical colleagues, there are remarkably few who are good at that. People in liaison psychiatry are few and far between but are probably the best trained to really be able to assess issues. The other problem is that the patient has to feel very safe in a very mutual environment to let you know if they have felt coerced. You only have to look at how difficult it is for people to admit to having been abused, even though they were aware that their life may have been threatened. If they are not in a safe environment, if they feel vulnerable, and if the person who has put some subtle pressure on them is

responsible for their care, they are very vulnerable because they may make their situation worse by speaking out against a person who is a carer. A situation which struck me hard was to hear about Mr Soffra who was murdered by one of his carers, his male nurse. He was a very wealthy man and was being cared for by health care professionals in a group and a team. This was meant to be done for personal gain and it all went terribly wrong. That is an extreme example but there is a worry about very subtle pressure and coercion and personal gain.

Q359 Mrs Humble: I am a little concerned at your comments that your colleagues saw your intervention to speak to your patient as being unnecessary and inconvenient. One of the dangers therefore is that with formal advance directives and especially advance refusals for treatment, particularly if enshrined in the Bill in the way that is outlined, other doctors will assume that, because it is a legal document, they do not need to address the situation again, even though the Draft Bill does talk about change of circumstances and therefore is assuming that there will still be a fresh assessment of capacity. Each of the assessments is for an individual set of circumstances. How can you get round that? Do you think it would be vital that we have a detailed code of practice so that clinicians do make sure that they are asking that question again about a person's capacity, especially given the context of a lack of a detailed process within the Draft Bill? There is not a detailed process that an individual has to go through in order to determine capacity. As a clinician, how are you going to deal with that? How can I ensure that, if I am the one who has made an advance refusal 10 years ago and I do not want it any more, I have a doctor like you looking after me rather than one who will not ask me again?

Professor the Baroness Finlay of Llandaff: There are two thoughts that come to mind. One is how long ago was it made and that is a huge problem because so many things may have changed in ten years. If it has been lying around at home and you have a relative who stands to gain from your death, if your life insurance policy expires in six weeks' time and they know that is in the drawer and you have not torn it up, they may run in with it and the clinician is then faced with being presented with a document that appears to be completely valid. I think I would like to see the responsibility of renegotiating an advance refusal prior to it being enforced. Advance refusals are very helpful for communicating with patients. It is terribly helpful as an idea of what patients want. My concern is that they are legally binding and then you may have to sit back and watch something happen that you just feel terribly uncomfortable with.

Q360 Mrs Humble: Would doctors feel threatened by legal action by relatives if the advance refusal was seen as being legally binding and non-negotiable?

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Professor the Baroness Finlay of Llandaff: I fear that they would, yes. The scenario of somebody brought into casualty already ill and the relatives coming in waving an advance refusal in your face is a real life scenario.

Q361 Mrs Humble: Unless doctors know that they can re-examine it because of the change of circumstances?

Professor the Baroness Finlay of Llandaff: It is not only can; I am concerned that it should be in order to ensure that patients are not denied treatment that could not only be potentially life prolonging but, more importantly, could improve the quality of life in the time that is left.

Q362 Baroness Fookes: Does that lead you to suggest that there should be no legally binding directives and that they should be advisory?

Professor the Baroness Finlay of Llandaff: My personal choice would be that they were always advisory but case law seems to have taken us beyond that point already.

Q363 Lord Rix: Could you think it possible for an advance directive to be written in such a way that it would allow for last minute adjustments, if clinical methods or modern drug methods had changed? Do you think it would be possible to write so that the wishes of the patient were clearly expressed but they were not absolutely legally binding when it comes to pulling all the plugs—thus ending life?

Professor the Baroness Finlay of Llandaff: The difficulty is that you cannot foresee every circumstance that may arise. Therefore, to try and write something for every circumstance that might arise would mean such an enormously complicated document that it would become unworkable. The reality is that patients are seen in the context of busy services that are under pressure. They are not seen in the context of services that have an infinite amount of time for each individual. They also are seen in the context of services staffed by people who are often very young, particularly on the nursing side. The average age of nurses on the ward is very young, even the senior nurses. My concern is that the fear of litigation by relatives will outweigh the courage to renegotiate and stand by what the patient has said. The difficulty is that once the patient is dead they cannot come back and give evidence on your behalf. To do things like tape record conversations and so on is just terribly burdensome and skews communication terribly, is frightening and would be cruel.

Q364 Mrs Browning: What you have been telling us has opened up many areas that I had not focused on. Yesterday, when we were talking to the BMA and psychiatrists, we were talking about patients who would have fluctuating degrees of capacity because they had a particular type of illness with peaks and troughs. I asked them, "When they are more stable, would you be actively encouraging them to write out one of these advance directives? Would you be proactive?" They all unanimously

said, "Yes." I am concerned about this because if you look at the population as a whole there is a huge number of people who do not make a will and for many of them it is not that they do not have anything to leave; it is that they cannot face their own mortality. They cannot deal with it. I am concerned that the trigger that would encourage people to do this would be something promoted by somebody else or would be done under what you describe as circumstances where they were very emotional because perhaps there was a constant health problem or some sudden change of circumstances. I am not sure how we are ever going to judge, in looking at what is proposed on the face of this Bill, not just the timescale of when it is written but how rational was that person? How much under pressure were they when they wrote it, because why would anyone think to write it unless they had a particular purpose for writing it because of a certain set of circumstances? That set of circumstances in itself could probably influence the motivation to do it anyway.

Professor the Baroness Finlay of Llandaff: I think you have hit on the nub of the problem. I am surprised if the BMA said they would always do it because if you look at discussions about cardiopulmonary resuscitation, which is about advance direction with patients who are very ill in hospital, it is an incredibly difficult thing to do. Within my own trust, we have been trying to develop a policy on it which is not offensive to people. However careful we have been, there have been some patients who have been absolutely terrified, thinking we are telling them that they are about to die.

Q365 Mrs Browning: In fairness, it was the psychiatrists who were enthusiastic.

Professor the Baroness Finlay of Llandaff: The problem relates to how do you know that the thing that is brought in is really what the person wanted? How do you know it was not superseded by another one? How would you ever discover if another one had gone in the shredder? How would you know about the conditions under which it was originally made and the proof? You have to take that in the context that a patient's complaint or a relative's complaint takes such an inordinate amount of clinical time and diverts you away from the job to be done to such an extent that it is every clinician's nightmare. The most difficult complainants are usually relatives after somebody has died. I can think of an instance at the moment where a patient was adamant that no information was to be handed to the family. The family are now complaining bitterly that they did not have the information and I think will dispute that that really was the patient's wishes, even though there is good documentation in the notes. The tensions that arise between the family members and patients I do not think should be under estimated. It gets even more complicated when you have other people coming in and giving care. Things like jealousy and guilt are very powerful emotions.

Q366 Chairman: If we had a smart card with all the medical information on, this is the sort of information which could be on there to show if there was an advance directive and, in that form, it would be updated from time to time, I imagine.

Professor the Baroness Finlay of Llandaff: I am a bit of a fan of the smart card. I think it would be helpful. At least there would be a single place where it was logged. It would be helpful if there was a single place where it was logged with a GP and I think it would be helpful to know that that was renegotiated. It would be helpful to know that the thing whipped out of the drawer by a relative was not valid. I would prefer to see the general practitioner as the custodian of the advance directive for a patient because they have known that patient when they were well, even if they have not known them very long because they have not had many conversations with them. They may be more reliable than a relative.

Q367 Jim Dowd: It is not smart cards but not very smart cards that cause more trouble. Are we losing sight of the point Baroness McIntosh was making on the status of the advance directive? As long as the patient has capacity it does not matter what they wrote ten years ago, five years ago or five weeks ago, because they can automatically override it, until such time as they do lose capacity. At that stage, with all the caveats and doubts that you outline about changing circumstances, surely it is the only guide you have to take you through that path? Do you fear being pursued by relatives because you did or did not carry out such a move?

Professor the Baroness Finlay of Llandaff: If the question is do I—?

Q368 Jim Dowd: I mean the legal profession generally.

Professor the Baroness Finlay of Llandaff: I am aware that it is a major distractor from the business of clinical care and wears people down. I have seen clinical colleagues who have been on the point of resigning, who have become profoundly depressed as a result of a complaint. I do not think the devastating impact of a complaint or a lawyer's letter on the clinical services should be underestimated. As I was saying previously, assessing capacity is very difficult and it can be relatively easy and dangerous to assume that somebody does not have capacity for that decision and not give them the opportunity for a lucid interval or give them the opportunity to communicate. You rightly refer to the problems of communication. A patient who has tremendous difficulty communicating may be able perfectly well to make a sound decision but unless people have to take the time to struggle with them, to establish that communication, they will be judged by everyone looking at them to lack capacity. If you take patients with motor neurone disease, who are dependent on a light writer to communicate, when they can no longer operate their light writer, they have all their faculties. They can hear and understand and process. It would be very easy to deem them to not have capacity for

decision. It may well be that they do not want any further treatment and they have that specified, or it may be that they have changed their mind and they would like to have, for instance, a gastrostomy done which previously they had declined or vice versa. I am concerned that the difficulties in communicating with people, the subtleties involved, are very hard to judge in law. Whilst it rightly says that you must assume capacity, I can see the scenario where people are labelled as not having capacity when they would have capacity for that specific decision if somebody took the trouble to spend time carefully renegotiating with them their advance directive, given the scenario now.

Q369 Jim Dowd: The presumption is that the advance directive is done in full knowledge when they have capacity, rather like wills. The first words of most wills are "I, being of sound mind". The presumption is that this is entered into by somebody fully understanding the consequences, without duress or coercion.

Professor the Baroness Finlay of Llandaff: What I was saying previously was however much you make it out for a situation that you think will arise the situation that does arise is usually slightly different to the one that you had envisaged at the time of making it.

Q370 Jim Dowd: You know that at the time of making it. You must if you can state it now.

Professor the Baroness Finlay of Llandaff: With due respect, I am amazed how often people think they will react one way when something happens to them and how very different their reactions are.

Q371 Jim Dowd: People are not the best judges of their own interests?

Professor the Baroness Finlay of Llandaff: I am not saying that; I think they are not the best judges of their future state of mind and reaction to situations.

Q372 Chairman: Would the Bill make these very complex decisions which you are describing better or worse?

Professor the Baroness Finlay of Llandaff: If you want an overall, global judgment, I would say something has to be done. Therefore, a lot of what is written down here is impressively good, if I can put a value judgment on it. I am not wanting to throw it out but my main concerns relate to the voluntariness of the principle. The wording did not come up here and I was looking for it.

Q373 Baroness Knight of Collingtree: I think we all ought to place on record our gratitude that at last we have someone before us, giving us evidence, who is actually at the coal face, dealing constantly with patients, day after day, and not merely the head of a trade union representing doctors because the difference in the evidence has been quite striking. I, for one, am most grateful to you for coming. Whether you have been able to go right through the Draft Bill I do not know but in your judgment if it became law what do you think would

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be the most significant positive and negative consequences for medical practitioners like yourself working all the time with terminally ill patients?

Professor the Baroness Finlay of Llandaff: Thank you. The positive is that there is some clear guidance formally written down in one place rather than a whole collection of different papers and different people's interpretation from different sources. We all know there are slightly conflicting words in the guidance that is currently out there. The best interest principle in here is very helpful because it would allow you to intervene more than people do at the moment. If I may go back to the confused hypercalcaemic who is very disruptive on the ward and worried about their safety, they just need a little sedation to tide them over. They will accept having hydration because they are so thirsty from their raised calcium level but they refuse anything else. They refuse to have anything by injection. At the moment, you cannot give them a small dose of something like haloperidol which they could take orally because you would be giving them a drug without their consent to it; but working in their best interest they would be much safer if they would calm down a little because by calming them down you may be able to negotiate the next step with them better and that would be in their best interests. That best interest principle is helpful. You also asked me about negatives. My biggest concern relates to relatives who are in dispute, who are pushing for interventions which may be futile or harmful or are pushing for interventions to be withheld. The patient is extremely vulnerable, being under emotional pressure and duress. I think there is also an issue for patients when they are facing their own dying. This goes back to the advance directives. They are very often worried about how their family will remember them. They do not want their family to have bad memories of them. Reconciliation within the family or the people they love and perhaps have been trying to reach out to emotionally for many years, where there has been a rift in the family previously, puts a very large emotional burden on people. That works against anything being renegotiated for mothers, particularly in relation to their children. They may be hesitant to renegotiate a situation which seems to go against what they have previously said to the family.

Q374 Baroness Knight of Collingtree: In the light of something Lady Finlay said, I may have been given the wrong information here. The words were that ultimately the doctor has the right to make the final decision—that is to say, about the care and the drugs for the patient—in the best interest of the patient. When you were answering me, you mentioned that you sometimes had a situation where you would like to give a patient a certain drug and could not. That did not seem to sit rightly with the information I had. I wondered whether I was wrong and whether it is true that the doctor has the right to make the final decision.

Professor the Baroness Finlay of Llandaff: There is a fine line always between saying that this refusal is clear and competent and saying that this refusal is in part clouded and in part incompetent and in part competent. If the patient is unconscious, it is easy. If the patient is flagrantly confused, it is easy. If they have an advance directive saying that in the event of them becoming confused they will not want any treatment, it becomes very difficult because if they stated that if they were confused and they are confused you know that you can do something to calm that confusion down. You know that you can treat it; you know that you can reverse it but you are faced with a document which is deemed to be legally binding which says, "If I was confused I would not want to be treated." Most lay people and most patients are terrified rightly of becoming confused and losing their dignity. Very few people are aware that a lot of causes of confusion are reversible.

Q375 Mrs Humble: This is a philosophical question. One of the things that has come out in all the evidence that we have been hearing and all the submissions we have had as a Committee is the fact that many people's value systems and beliefs do vary. How can we in this Draft Bill marry up respecting a person's wishes on the one hand and respecting life on the other?

Professor the Baroness Finlay of Llandaff: Some people do not want to live. They commit suicide. They take an overdose. The difficulty is that when they have a little bit of time sometimes they change their minds. I can illustrate this with a clinical example of a patient who took a massive overdose of Paracetamol. He did not want to come to hospital but was persuaded to. He flatly refused any intervention or any treatment. Two psychiatrists who are colleagues of mine spent a lot of time negotiating with him for several days and explained absolutely everything that might happen to him in graphic detail and he was adamant he wanted no treatment. They warned him of every scenario, including coughing up blood as he started to haemorrhage to death. When he started vomiting blood, he changed his mind and requested treatment. He ended up being transferred to King's for a liver transplant. That illustrates the difficulty of patients' belief systems and what they really think they feel and what they do when they are facing the final buffers and the very end of their life. The difficulty too is where you have other belief systems and structures that come in. At the end of the day, I would return to a statement I have made on the floor of the House that the law has to veer towards protecting life and has to work to preserve life but life that has quality. Therefore, you also have to preserve life and respect death when it is coming, but I worry that there is a tendency to almost be too accepting of death as an inevitable outcome with some diseases and some processes where, although it is inevitable, a little bit more time might be very valuable. Without an onus to renegotiate always and to relook at a situation clinically as it arises, it is very, very easy to accept

perceptions and value judgments that were previously made. I do not know how you can enshrine that in law and I worry about the law trying to cover all eventualities in society because I do not believe it ever can. It just simply has to work to protect the most vulnerable and the majority.

Q376 Mrs Humble: One of the issues is not the case where you can renegotiate because that person would still have the capacity to deal with that. It would be the case of somebody who had, for example, made an advance directive to refuse treatment and appointed somebody with lasting power of attorney to deal with that. That individual is in the hospital, is incapable of making a decision but you as a clinician would be required to carry out those final wishes because you did not have somebody to renegotiate with. The person with the lasting power of attorney would be carrying out those last wishes.

Professor the Baroness Finlay of Llandaff: I see that as a huge clinical dilemma and also because drugs do not have single, targeted effects. For instance, if somebody has a chest infection and is distressed and coughing up horrible, thick sputum, by giving them antibiotics they may be much more comfortable. You might make no difference to the

overall course of the disease, but it may be that it turns out to be a life prolonging action. If it was a life prolonging action, you would have been acting counter to an advance directive. If it was making them more comfortable, you would not have done. I do not think you can always foresee ahead the results of an intervention that you make. That is truly the dilemma that one is faced with. You take a decision at one point in time on the balance of probabilities of the outcome but the unexpected can occur and you would have known it was a possibility but it was perhaps very low on the list of possibilities.

Q377 Chairman: From what you have said, I think you may have some sympathy for the Members of the Committee having to report on all this and trying to draw conclusions. Thank you very much indeed. It has been a very helpful session.

Professor the Baroness Finlay of Llandaff: Thank you. Perhaps the Committee will have sympathy for hospice doctors.

Q378 Chairman: If you wish to write to us on anything else, please do so.

Professor the Baroness Finlay of Llandaff: There was a very good paper in the BMJ a while ago and I will print that out and bring that to you.

12. Supplementary memorandum from the Baroness Finlay of Llandaff (MIB 1208)

I am most grateful to the committee for giving me the opportunity to address you today. I had one other point to make, which may appear trivial, but I hope may help avoid confusion.

I commend the term "Advance Decision to Refuse Treatment". It will need to be carefully promoted as "Advance Decision" or "Advance Refusal", rather than the current misleading term in common use: "Advance Directive". The term "Advance Refusal" may avoid confusion in anyone's mind as to what the patient can and cannot decide in advance.

It would clarify that the patient cannot "direct" something to be done to him or her that is deemed futile, in the vain attempt of prolonging life (eg intravenous chemotherapy for refractory advanced cancer; to continue ventilation when massive brain damage and no possibility of recovery of spontaneous respiration). Equally, the patient cannot demand an intervention to foreshorten life—eg injection of barbiturate and curare to cause death. I realise the Bill does not allow for the patient to demand an intervention, but the term Advance Refusal may be a safer descriptor of the document. I apologise for omitting this earlier today in response to Baroness Knight of Collingtree's question.

I also welcome the best interest principle. It will be important that the accompanying guidance makes clear that the views of those specified in 4 (2) (d) should be consulted but that their opinion cannot override the clinician's decision to act according to their consideration of "best interest". Without this made clear, the clinician will be the puppet of conflict between for example, family members or family member and employed carer.

In relation to the severely ill, psychiatric disease is easily missed as many of the pointers to treatable depression are similar to the symptoms and signs of, and appropriate responses to systemic disease: eg loss of appetite, loss of libido, fatigue, sleep disorder, pessimism about self and the future. States of high emotional arousal, such as a broken relationship or the parent whose child (of whatever age) is dying, can distort the ability to take decisions.

I touched on, but may not have made clear, my concern over the code of practice guidance. There is no definitive test of competence; it is a considered clinical judgement and each test used will only give you results to the specific questions asked. Also, the very process of an assessment took is very tiring for someone who is very ill, so they may become fatigued into incompetence by the process of assessment. Any guidance should be very simple and avoid more form filling by professionals, since form-filling tends to detract from true sensitive communication. One paper that I referred to, which the BMJ published, is: Barbara Hewson.

The law on managing patients who deliberately harm themselves and refuse treatment. *BMJ* 1999;319:905–907. Full text is available on the British Medical Journal website <http://bmj.bmjjournals.com/cgi/content/full/319/7214/905>.

Another very useful text is the book “The Diving Bell and the Butterfly” by Bauby, which describes his experience of locked-in syndrome when he was considered to be incompetent, but actually could see, hear and think but had no movement at all to signal anything to those around. A speech therapist realised he had a single eye muscle movement to communicate with and she helped him to dictate the whole book using predictive spelling with a single eye movement. He died shortly after it was published. It is a short book and I would really recommend the committee to try to read it as it gives the patient’s perspective beautifully and the dangers of communication difficulties.

I hope this is of some help.

October 2003

13. Joint memorandum by the Catholic Bishops’ Conference of England and Wales and the Linacre Centre for Healthcare Ethics (MIB 1001)

INTRODUCTION

1. We¹ welcome the opportunity to comment on the Draft Mental Incapacity Bill which the Government has proposed. In so doing, we focus on health-related issues: we do not comment on the Draft Bill’s provisions on financial matters, which may indeed be useful in protecting the interests of those with mental incapacity. In contrast, we believe that the provisions of the Bill relating to health, while these may be similarly well-intentioned, will in fact exacerbate threats to the lives and health of mentally incapacitated people.

2. There are four points we wish to make briefly:

- A. lack of effective safeguards against suicide and homicide by omission;
- B. weakness in the definition of “best interests”;
- C. dangers in the proposed scheme for proxy decision making; and
- D. dangers inherent in enforcing advance directives in the manner proposed.

A. LACK OF EFFECTIVE SAFEGUARDS AGAINST SUICIDE AND HOMICIDE BY OMISSION

3. Existing case-law already permits patients in a persistent vegetative state to have “treatment” (including tube-feeding) withheld with the aim of causing death.² In permitting omissions, though not actions, with a homicidal purpose, the law has been left, in the words of one Law Lord, in a “morally and intellectually misshapen state”.³ The Draft Bill does nothing to reverse this unfortunate situation; nor does it stipulate that life-sustaining measures may not be withheld from non-P VS patients with the aim of causing death. The Bill does not distinguish between choices on the part of doctors, patients or proxies with the aim of causing death and choices with the aim of avoiding the burden of certain interventions. Rather, in emphasising the need to respect the patient’s past “wishes and feelings”—whatever (it appears) they may be—the Bill would apparently require doctors to respect advance refusals which are suicidally motivated; ie, where the patient’s aim was to end a life predicted to be not worth living. Indeed, the Bill would apparently permit doctors intentionally to assist such a suicidal refusal. Similarly, proxies who wish to end the patient’s life—whether for the patient’s sake or for their own—will evidently have full power to do this, on claiming this is what the patient wanted.⁴ It is the doctor who seeks to override a suicidal or homicidal refusal (and so protect the patient from death or disability) who would seem to be made liable to criminal proceedings.

¹ This Response has been prepared by Dr Helen Watt, the Director of the Centre, in consultation with Professor Luke Gormally, Senior Research Fellow at the Centre, and Professor John Keown of the Kennedy Institute of Ethics. For a more detailed account of our approach to healthcare decisions for the mentally incapacitated, see John Keown and Luke Gormally, “Human Dignity, Autonomy and Mentally Incapacitated Persons: A Critique of Who Decides?” [1999] 4 Web Journal of Current Legal Issues, at www.webcli.ncl.ac.uk/1999/issue4 and the Linacre Centre Responses to Who Decides and Making Decisions, at www.linacre.org.

² See *Airedale NHS Trust v Bland* [1993] AC 789.

³ *Bland* [1993] AC 789 at 887, per Lord Mustill.

⁴ The Bill does contain a clause [Ill. 31] on the mistreatment or neglect of incapacitated people. However, by defining “best interests” of the incapacitated person solely in relation to that person’s actual or hypothetical desires [1.4], the Bill, in conjunction with existing case-law, would appear to allow proxies to refuse treatment with a homicidal motive, providing the refusal is defended in terms of such desires. We would urge that clause 1.31 proscribe any refusal of treatment or care which is based on the aim of hastening death—whether this aim be that of the carer, proxy and/or the patient at an earlier time.

⁵ See note 4.

4. We would urge that treatment should in no case be withheld with the aim of causing death: this should be a criminal offence whatever the patient's state of health.⁵ It is important to recognize that proscribing choices made with the aim of ending life would not commit anyone to pursuing or agreeing to medical treatment which is futile or burdensome. What needs to be stressed here is the key distinction between aiming to end life (albeit by omission), and not aiming to prolong life by inappropriate means.

B. WEAKNESS IN THE DEFINITION OF "BEST INTERESTS"

5. We are alarmed by the reduction of the patients' interests to subjective "wishes and feelings" of the patient in clause 1.4. It is remarkable that the Draft Bill makes no mention, in what it says about the patient's best interests, of the interest in life and health.⁶ While not the only aspect of a person's welfare, life and health is certainly one aspect, which traditionally the medical profession has been committed to promoting. To ask doctors to ignore the health interests of patients wherever the patient had, in the past, some conflicting "wish or feeling" is to ask doctors to abandon their traditional role in caring for incapacitated people.

C. DANGERS IN THE PROPOSED SCHEME FOR PROXY DECISION MAKING

6. The Draft Bill gives significant powers to proxy decision makers, and grants them legal status in the context of health care. There are, however, risks in giving such powers to those not medically qualified, who are not like doctors held accountable for medical negligence, and who may even have a conflict of interest such as a financial expectation on the patient's death. As presently drafted, the Bill gives proxy decision makers power without accountability. At the very least there needs to be a prescribed duty of care and accountability in law for decisions taken by the donee of a lasting power of attorney or a deputy appointed by the court. The donee or deputy should be required to give due weight to the patient's health interests, and not simply to his or her desires at some earlier time. Furthermore, in the case of a dispute between the donee or deputy and a doctor there should be reference to a second independent medical opinion, and if the matter still cannot be resolved, a reference to the court.

D. DANGERS INHERENT IN ENFORCING ADVANCE DIRECTIVES IN THE MANNER PROPOSED

7. Competent patients do, of course, have first responsibility for their own health: a responsibility which extends a certain way into periods of incapacity. With regard to advance refusals, there is no objection to doctors following a refusal which is recent, well-informed and is not suicidally motivated. However, the same cannot be said of a refusal which is made on the basis of inadequate information and/or has the aim of ending life. Those who are, or have been, suicidal need to be treated in their objective interests, not to have their lives ended out of 'respect' for their wish that this be done. If patients, living as they do in a society which devalues the lives of disabled people, act on the basis that such a life would be worthless and should be curtailed, this is not an intention which it is in their interests, or society's interests, to respect.

8. Advance refusals will often be ill-informed: unlike the situation with contemporaneous refusals, the person making the advance refusal may not have been offered any information (for example, by a doctor) on what he or she is refusing. (In particular, those refusing "treatment" may not realise that tube-feeding is classed as treatment in the law.) The Bill is vague on what is to count as an advance refusal, merely saying that such a refusal may be expressed "in broad terms and non-scientific language" [1.23(2)].⁷ Previous information from the Lord Chancellor's Department suggests that even passing oral comments by the patient could have legal force.⁸ (Certainly, a proxy may refuse treatment on the basis of just such an informal statement.) While wills disposing of a person's financial assets rightly have a strict form, it is anomalous that advance refusals—which may result in death or increased disability for the patient—could be so vaguely specified and still be binding on doctors. In the Bill, it seems that advance refusals are "valid unless proven otherwise": in practice, the onus of proof will be on anyone who wants to treat the patient to show that a purported refusal is not, in fact, binding. For many patients, there will be no-one to challenge the claim that a binding refusal has been made.⁹

⁵ See note 4.

⁶ This interest was strongly emphasised by Lord Brandon in *Re F*, who held that treatment of noncompetent patients was in the best interests of such patients only if "carried out in order either to save their lives or to ensure improvement or prevent deterioration in their physical or mental health" (*Re F v West Berkshire Health Authority and Another* [1989] 2 All ER 545, at 546).

⁷ Any legislation on advance refusals of treatment should require that these be well-documented, witnessed to by two witnesses without a vested interest in the estate of the patient, based on accurate medical information and motivated otherwise than by a desire to end one's own life. In the current Bill, a paragraph to this effect might be inserted to replace 1.23 (2), which is far too vague in counting as valid refusals those "expressed in broad terms".

⁸ Making decisions: A guide for social care professionals, p.18.

⁹ We are also concerned that it will be difficult and time-consuming for patients who have regained capacity to cancel an advance directive or power of attorney (see Schedule 3, Part 4, 14: 1-2). Given the life-and-death issues at stake, it should, at the very least, be more difficult to make, than to cancel, such arrangements. Moreover, the Bill makes no provision for patients without capacity to show by their behaviour (signs of hunger, distress at a treatable condition) that their wishes have changed.

9. In some cases, even a well-informed, non-suicidal advance refusal should, in our view, be overridden, though this would certainly be the exception. In particular, an advance refusal of pain relief, hygienic care or feeding—whether orally or by tube—should not bind absolutely. Patients should be given a minimum level of care, both for their own sake and for the sake of protecting an ethic of care on the part of doctors and nurses. It needs to be stressed that incapacitated people have objective health interests, which doctors and nurses should be permitted to promote to a certain basic standard. No advance directive, and no attorney or deputy, should have the power to refuse such basic interventions in the patient's interest. This should be stated on the face of the Bill.

September 2003

14. Memorandum from the Joint Ethico-Medical Committee of the Catholic Union of Great Britain and the Guild of Catholic Doctors (MIB 781)

The Joint Ethico-Medical Committee is composed of members drawn from the two parent bodies. The Catholic Union is an organisation of the Catholic laity which is not affiliated to the hierarchy but which represents the Catholic viewpoint, where relevant, in Parliamentary and legislative matters. The Guild of Catholic Doctors represents Catholic Medical Practitioners in the United Kingdom.

SUMMARY

In the Bill:

- There is no legal definition of “best interests”, only a list of matters to be considered, with reliance on presumed wishes and feelings of the incapacitated patient.
- There is no provision of an independent second medical opinion or appeals process before taking matters to the court.
- The lasting power of attorney has considerable power with no accountability. This opens the possibility of withdrawing nutrition and hydration or other measures with the intention of ending life. There needs to be a prescribed duty of care and accountability for decisions taken.
- There is no registration, validation of the authenticity or process to establish that an advance directive was made by a person whilst they had mental capacity.
- It appears that several of the recommendations are contrary to the articles of the European Convention of Human Rights.

We consider that:

- Advance directives should be advisory and not mandatory. Current case law is sufficiently robust to enforce advance decisions in circumstances that would be acceptable to all.

GENERAL POINTS

1. In this submission we will restrict ourselves to those matters covered in the draft Bill which affect the medical care of those with incapacity.

2. We welcome the principle of the Bill's proposed protection of the welfare needs of persons lacking capacity and the introduction of the principle of a “general authority” where actions of medical personnel, which have previously been performed using the principle of “necessity”, will now have a legal basis.

3. We welcome the Government's statement made recently that there is no intention to change the law on euthanasia, which will remain illegal. However we note that the Government definition of euthanasia is “a deliberate intervention undertaken with the express intention of ending a life . . .” (Annex C), whereas the Catholic understanding of euthanasia is “Euthanasia in the strict sense is understood to be an action or omission (our emphasis) which of itself and by intention causes death . . .” (*Evangelium vitae* 65). This may lead to serious issues of conscience for many healthcare staff in some situations of the withdrawal of nutrition and hydration, which we will refer to later in this submission.

4. The implementation of the Scottish Mental Incapacity Act has shown that the complexity of the legislation has led to difficulties in delivering good medical care; eg it has proved difficult to administer 'flu vaccine to demented patients without going through a complex administrative process. We therefore suggest that legislation affecting medical care in this area should be permissive, to be used only when necessary, rather than mandatory and applying to all medical care of mentally incapacitated patients. Eg—if there is a lasting power of attorney it could seriously hamper good medical care if consent had to be sought from the attorney for every medical decision taken.

CLAUSE 2—INABILITY TO MAKE DECISIONS

5. We acknowledge that determining mental incapacity can be difficult and point out that in the context of a busy A&E department, the most that can be expected from busy junior doctors is an assessment of a patient's orientation in time, place and person using indices such as the "Mini Mental Test"—a list of 10 simple questions. This gives a working indication of their mental state but has limitations and would not seem to constitute a formal assessment of mental incapacity according to this Bill.

6. Subsection 1 (b) We suggest that not only does a patient need to retain the information, they also need to believe it. Eg a person suffering from paranoia. We also suggest that it is important to be confident that the patient does not feel either external or internal pressure which may hinder them in making a decision as in [Re: T (Adult: refusal of treatment) [1992] 4 All ER 649)] where it was deemed that the advance refusal of blood transfusion, by a pregnant Jehovah's Witness, had been invalid as it was made under duress.

CLAUSE 4—BEST INTERESTS

7. We are seriously concerned that there is no legal definition of a person's "best interests", but only a list of matters to be considered. It is important to clarify that in the healthcare setting the medical best interests, as determined by the patient's doctor, must be taken into account. Once the patient's condition and circumstances has been assessed, a decision needs to be made taking any other relevant factors into account. However, we do not believe that the "best interests" of the patient can be properly considered without regard to their clinical need.

8. The best interests of an individual can be regarded from different aspects. Healthcare professionals are primarily concerned with their patients' medical/clinical best interests, which are directed to preserving life and promoting good health. The purpose of medical treatment is to cure or alleviate a pathological process and is directed towards the restoration of physical and psychological well-being of the person and the alleviation of pain and suffering. Where life is approaching its natural end, treatment should be palliative.

9. We accept that a person with capacity can exercise their right of autonomy and act contrary to their best interest. However a difficulty arises when considering substituted capacity (either as a general authority or lasting power of attorney). There is no provision in this Bill for the resolution of a conflict when the presumed wishes of an incapacitated patient are at variance with a common view, or a medical view, on what is in a person's best interest. The legislation needs to recognise that an individual's wishes may be very different from their "best interests" particularly from a medical point of view. In the medical context there is a need for a quick and simple method to resolve conflicts between an attorney's and clinician's view on what is a patient's best medical interest, otherwise medical harm may be done.

10. Clause 4 Subsection 2(a). We suggest that this section is badly drafted. The explanatory notes indicate that the intention of this section is that if a period of incapacity is likely to be temporary, then delay in making a decision should be considered so that the person themselves can make the decision on recovery of the capacity. However, as the Bill is written this clause could imply that what is in a person's best interests is dependent on whether they are likely to have capacity in the future, and as such can be construed to mean that those with permanent incapacity should be treated medically differently to those who are likely to regain mental capacity.

11. Limiting consideration to "his past and present wishes and feelings" is totally inadequate in the medical context. For instance, a depressed or suicidal patient may wish that his life should no longer continue and acceptance of this patient's wishes and desires would therefore lead to medical decisions against giving life sustaining or curative treatment.

12. Clause 4, Subsection 4. Doctors accept that patients have a right to refuse treatment, even though their reasons for doing so may be irrational. Healthcare professionals have a duty to provide best possible medical care and are accountable for a failure to do so. However, under this Bill attorneys or deputies can make decisions to refuse treatment which are binding on healthcare staff, without any corresponding accountability for such decisions. We believe that the phrase "if the person reasonably believes that what he does or decides is in the best interests of the person concerned" will be a unassailable defence against even the most gross violation of "best interests".

13. We suggest that the attorney must present firm evidence that he or she truly understands what they are proposing and that "informed consent" is contemporaneously applicable; that is to the current situation.

CLAUSE 6—THE GENERAL AUTHORITY

14. We support the concept of general authority, and the provision of a legal authority to do what doctors have previously done under the "rule of necessity".

15. The experience of some of our colleagues in Scotland has highlighted that the working of the lasting power of attorney has led to burdensome bureaucratic procedures which have impeded the administration of routine medical care. We would expect that most routine care will continue to be provided under common law.

CLAUSE 7—RESTRICTIONS ON THE GENERAL AUTHORITY

16. Subsection 1(a). We commend the final paragraph of this clause. It is often necessary to restrain incapacitated patients when administering medication. For instance a diabetic suffering from hypoglycaemia may become extremely aggressive and the urgent administration of intravenous glucose, usually whilst restraining the patient, is vitally important and instantly curative.

17. Subsection 2. We are concerned that a decision by the donee of a lasting power of attorney will override the medical decision of the healthcare team. There is no provision in the Bill for a second independent medical opinion procedure in the case of disputes between the attorney and doctor. In Scotland, disputes are first referred to a second opinion doctor. If they cannot be resolved then interested parties can apply to the Court of Session to determine if the treatment may proceed. There is no such provision in the current Bill and disputes would need to be referred directly to the Court.

18. The courts have a primary role in addressing matters of law and not the merits of a particular medical treatment. We are concerned that when cases are referred to the Court, it will, quite properly, concentrate on the legality of the decisions made by the donee of a lasting power of attorney and not properly address the merits of the medical treatment being disputed by the attorney, to the potential detriment of the patient. Hence our suggestion for an independent medical opinion or appeals process prior to any court process.

19. Subsection 3. The Catholic (and other religions) understanding of euthanasia is an act or omission to bring about the death of a patient. We believe that provision of food and fluids normally constitutes part of basic care necessary to sustain life. We believe that there are many circumstances where the removal of nutrition and hydration (including some cases authorised by the Courts) constitute euthanasia by omission and so are contrary to the conscientiously held views of many. The religious principles of a substantial body of those working in healthcare need to be preserved and upheld. In the same way that patient's religious views are accepted, so too the religious views of healthcare personnel must equally be respected.

CLAUSE 8—LASTING POWERS OF ATTORNEY

20. We believe that medical management of the mentally incapacitated should remain with healthcare professionals who, as a matter of good clinical practice, should consult the patient's nearest relatives, carers and attorney. Involvement of the attorney should be regarded as evidence of acting reasonably under the circumstances. If the attorney is to be empowered to make clinical decisions, they also should be under a duty of care in civil law to the patient for wrongful decisions. In Scotland, according to the Regulation of the Adults with Incapacity Scotland Act (2000), welfare attorneys have a duty of care under common law:

“6.1 An attorney, guardian or other person acting under the Act is held at common law to owe a duty of care to the adult with incapacity. They must act with due skill and care in exercising the power they have been given in relation to the adult. A professional person acting as a proxy must demonstrate the skill and care that would be expected of a reasonably competent member of that profession.

6.2 An attorney has what is known as a ‘fiduciary duty’ to the granter. This means that you are in a position of trust with repeat to the matters covered by your powers. The adult has placed trust in you to exercise the powers properly.”

CONFLICTS OF INTEREST

21. The attorney will have the power to refuse medically advised treatment. The attorney may also have power over the patient's financial affairs. The explanatory notes (Annex A, para 4) highlight that there may be financial abuse in 10-15% of enduring powers of attorney. There will certainly be circumstances where the family will benefit financially from the patient's death, and under this bill the donee will now have the power to refuse treatment and so hasten that patient's death. This potential conflict of interest is not addressed in this Bill.

CLAUSE 10, SUBSECTION 4

22. We suggest that there is an additional paragraph which specified that basic treatment and care cannot be refused. Basic care consists of those measures necessary to the survival of the person. (see also our comment on Clause 17(d) below)

CLAUSE 12, SUBSECTION 2

23. There is a contradiction between this section, which simply states “P may, at any time when he has capacity to do so, revoke the power”, whilst Paragraph 14, sub-paragraph 1(a) of Schedule 3, Part 4 states that “no revocation of the power by the donor is valid unless and until the court confirms the revocation under paragraph 15(3)”. This would certainly appear to prevent an immediate revocation of the kind which might be necessary in a medical emergency.

CLAUSE 17, SUBSECTION (D)—SECTION 16 POWERS: PERSONAL WELFARE

24. We note that the Law Commission document “Mental Incapacity” (Law Comm 231, 1995) stated that no court, attorney or deputy should be permitted to refuse “basic care”. This is no longer present in the current Bill. We support the original Law Commission recommendation and add that basic care not only includes food and fluids, but the continuation of ordinary care already being given—eg we do not believe that it is acceptable to withdraw insulin from a long-standing diabetic as part of the decision to withdraw medical treatment on the grounds that it is futile or burdensome.

25. We accept that the placing of a feeding tube should be regarded as a medical procedure, but we would argue that the administration of food and fluids through an established feeding tube is normally part of basic care and should not be regarded as “medical treatment” which can be refused or withdrawn. (There are rare circumstances where the food and fluids cannot be absorbed and so can be withdrawn as continuation of administration will not achieve its purpose).

CLAUSE 23—ADVANCE DECISIONS TO REFUSE TREATMENT: GENERAL

26. It is a key principle of informed consent and good medical practice that a patient must have an explanation of the risks and benefits of a specified treatment, as well as an explanation of the potential consequences of refusal of that treatment (if a patient indicates they wish to refuse treatment). We therefore accept in principle that a patient can give an advance refusal of treatment, but we would wish there to be a system of validation of such an advance refusal.

27. We believe that case law has already established the principles of advanced refusals, particularly the judgment of Mr Justice Hughes in the case *Re: AK* (High Court of Justice, Family Division: Hughes J. (2000) 58 BMLR 151; [2001] 1 FLR 129) and suggest that this judgement should be a basis for accepting advance refusals and specified in the Act. Mr Justice Hughes said:

“It is . . . clearly the law that the doctors are not entitled so to act if it is known that the patient, provided he was of sound mind and full capacity, has let it be known that he does not consent and that such treatment is against his wishes. To this extent an advanced indication of the wishes of a patient of full capacity and sound mind are effective. Care will of course have to be taken to ensure that such anticipatory declarations of wishes still represent the wishes of the patient. Care must be taken to investigate how long ago the expression of wishes was made. Care must be taken to investigate with what knowledge the expression of wishes was made. All the circumstances in which the expression of wishes was given will of course have to be investigated. In the present case the expression of AK’s decision are recent and made not on any hypothetical basis but in the fullest possible knowledge of impending reality.”

28. In the majority of advance refusals of treatment, which are currently being proposed by various organisations, there is no way to establish what understanding the patient had of the risks and benefits of treatment, and more significantly whether they were fully aware of the consequences of refusal. Advance directives, rarely if ever, meet the standards of informed consent that is required from patients with capacity. The wording of the Bill “. . . expressed in broad terms or non-scientific language.” is an antithesis of case law and the principles expressed in other areas of the Bill, ie that the circumstances and treatment must be specified.

29. There are regulations which must be adhered to in order to accept the validity of a last will and testament. This Bill gives no indication of how the medical team are to assess the validity of an advanced refusal of treatment. The Bill does not even specify that an advance decision needs to be in writing. Situations could be envisaged where the relatives would prefer that an aged incapacitated patient died. They may fraudulently prepare and present an advance directive worded so that it appears to be specific and applicable to the current situation. Without prior registration of such a document with medical authorities, where it can be validated that it truly was made by the patient and whilst they had capacity, how are the medical team expected to even make the simplest judgment about its validity?

30. When considering refusal of treatments in patients with capacity, the clinicians will verify with the patient that they understand implications of refusal, and established practice is that the patient is normally asked to sign that they are refusing such treatment. There is no way of assessing in an advance directive that the patient does understand the potential consequences of refusal of treatment, even though they may have specified refusal of life-sustaining treatment. It may well be that refusal does not lead to death but leads to worsening disability and increased suffering.

31. There is no logic in the Bill limiting advance directives to refusal of treatment. It is now common medical practice to prepare a treatment plan for patients suffering with progressive degenerative diseases whilst they still have the capacity to make decisions. Such a treatment plan will include both therapy they would wish to receive as well as those they would wish to refuse. However such plans are regarded as advisory and circumstances may occur which would override the original treatment plans.

32. Another example where legally binding advance refusals of treatment can be dangerous is in women presenting their obstetricians with “birth plans” on how they would like their delivery to proceed—eg these may state refusal of forceps delivery etc. When the delivery is proceeding well such plans can be fully respected. However if complications then arise, it may be the case that the woman has already been sedated

sufficiently to make her mentally incapacitated within the meaning of the Bill, and adherence to the directives of the “birth plan” could result in brain damage to or death of the baby. Clinicians in our own committee have direct experience of such circumstances.

33. For these reasons we strongly argue that advance directives should be respected as advisory documents, and we believe that current case law is sufficiently strong to allow patient’s wishes to be respected, but equally allowing appropriate medical treatment to be given when the situation demands.

CLAUSE 24—VALIDITY AND APPLICABILITY OF ADVANCE DECISIONS

34. Our preceding and following comments clearly explain our concern at the proposed legally binding nature of advanced directives as laid out in this Bill. We clearly state our view that legislation will make it very difficult for practitioners faced with the need to make rapid decisions in acute medical emergencies to easily and clearly decide when an advance directive is valid and applicable. Fear of litigation may well result in doctors withholding appropriate care with resultant harm to the patient.

35. Subsection 1(a). There is no definition of what constitutes a valid advance decision, or how it is to be established.

36. Subsection 1(b). This should read at least “clearly applicable to the treatment”.

37. Subsection 4(c). This should read at least “circumstances and treatment opportunities which were not clearly understood or clearly anticipated by P at the time . . .”

CLAUSE 25—EFFECTS OF ADVANCE DECISIONS

38. There has been extensive debate about the morality of the Bland judgment which declared that food and fluids can be regarded as medical treatment and therefore withdrawn. There is a considerable body of medical opinion that believes that elective withdrawal of nutrition and hydration given through an established feeding tube is euthanasia and therefore ethically unacceptable. This Act gives no protection to those members of the healthcare team who hold such views as part of their religious/ethical convictions. We ask that the Act allows for those with conscientious objection to refuse the implementation of some forms of advance directive without the individuals concerned suffering any professional harm.

39. We accept specific advance refusals of treatment such as in *Re: C*, (Adult: refusal of treatment) [1994] 1 All ER 819—the Broadmoor patient who refused an amputation, where the circumstances were present whilst the patient had capacity and the consequences of refusal were clearly explained. We also accept the principle that Jehovah’s Witnesses may wish to refuse all blood transfusions. We are strongly opposed to blanket refusals of a wide spectrum of treatments in a broad set of circumstances, that cannot be known about at the time the advance refusal is drawn up. We note that subsection 1 provides that “the advance decision will need to specify the treatment that is refused and may specify the circumstances in which the refusal will apply” (Explanatory notes). However, below is a typical format of an advance refusal currently being presented to doctors:

5. If I have any condition described in paragraph 4, above, I direct that all procedures which might prolong my life be withheld or withdrawn, and that I be permitted to die with only the performance of any medical procedure necessary to provide me with comfort or to alleviate unnecessary pain. Specifically, but without limiting myself, I do not want surgery, medication (except pain relief), cardiopulmonary resuscitation, antibiotics, kidney dialysis, blood transfusions, radiation or chemotherapy, or a mechanical respirator.

6. I do NOT want my life prolonged by tube or other artificial feeding or fluids if my condition is as stated above in paragraph 4.

40. We believe that this is a broadly based blanket refusal of all treatment, which should not be regarded as valid, despite it specifying the circumstances and specifying refusal of almost all or any treatment. If such an all embracing list of refusals were to be acceptable under the present Bill, proper treatment in accordance with medical criteria would effectively be excluded. We argue that the above example of refusal of treatment is made on a hypothetical basis without the fullest possible knowledge of the impending reality.

41. We can also envisage the scenario where a suicidal patient may prepare an advance directive which clearly specifies that they have taken a particular drug and then specify that they refuse to have their stomach washed out or receive the specific antidote to that drug. According to this Bill, the circumstances and life saving treatment being refused will be very specifically addressed making that advance directive legally binding. The doctors will then be legally barred from attempting to resuscitate that patient. It could even occur that the overdose is not fatal, but that the patient is left with significant permanent and disabling organ damage. It is because of likely scenarios such as this that we oppose making advance refusals of treatment legally binding, other than in the circumstances already present under case law. (*Re: AK* quoted above)

42. Clause 25 subsection 2. We would suggest the addition of paragraph (c). “he has reasonable grounds to doubt the validity of an advance directive.”

43. Clause 25 subsection 3. We propose that there must be some accountability for decisions made on behalf of the incapacitated. Granting immunity to one who withholds or withdraws treatment merely on the basis "in the belief that that a valid advance decision is applicable . . ." and that "his belief is reasonable" is an inadequate safeguard where life or death are in question. Furthermore it is not clear whether such "belief" relates to the interpretation of known advance directive or to the alleged existence of an unseen one.

CLAUSES 26—29. EXCLUDED DECISIONS

44. We would suggest the addition of clauses which state that no one can make decisions relating to abortion, sterilisation or non-therapeutic research on behalf of a mentally incapacitated person.

CLAUSE 30—CODES OF PRACTICE

45. We submit that the Codes of Practice should be prepared at an early stage and presented as part of the legislation. In this way it can be seen how the Act is to work in practice, with particular emphasis of its impact in the day-to-day delivery of healthcare to those with mental incapacity. We fear that implementation of the Bill may hamper delivery of good medical care, as is being experienced in Scotland with the working of their equivalent Act.

CLAUSE 32—CONCEALING OR DESTROYING ADVANCE DECISION TO REFUSE TREATMENT

46. The Bill provides no criteria for the establishment of the validity or the date of an advance directive, so how can it be that a person can be found guilty of concealing or destroying another person's written advance directive?

HUMAN RIGHTS

47. We have been given an opinion by Mr Richard Gordon QC, a human rights lawyer, that the bill is contrary to the European Convention on Human Rights. Specifically he states that:

- (a) The Mental Incapacity Bill is incompatible with Article 2 taken in conjunction with Article 6 of the European Convention on Human Rights because it fails to comply with the State's obligations under Article 2 to provide practical and effective protection of the right to life.
- (b) In particular, the concept of "best interests" in the Mental Incapacity Bill is defined by reference to criteria that are, at least primarily, relevant to autonomy as opposed to best interests. The decision-making powers of the donee of the lasting powers of attorney are made by reference to such criteria but leaving an area of judgment to the donee that is neither statutorily defined nor protected by access to the Court within the meaning of Article 6. Similar concerns arise in respect of exercise of the general authority.
- (c) The machinery of recognition and implementation of advance decisions to refuse treatment are similarly contrary to Article 2 because they provide wholly inadequate protection for safeguarding the best interests of persons entitled to protection under Article 2 at the time that life saving medical treatment falls to be considered.
- (d) Article 14, protecting as it does against discrimination in the enjoyment of Convention rights, appears to discriminate between those incapacitated persons who can communicate objection to certain proposed conduct (see clauses 7 and 10) and those who cannot. Such discrimination is neither logical nor (therefore) objectively justified under Article 14.

August 2003

15. Memorandum from Dr Adrian Treloar (MIB 679)

I am writing to you as an Old Age Psychiatrist working in a district clinical setting to express my concerns about some aspects of the legislation now being proposed. I shall be brief and try to make discreet points. Firstly however, I should say that the principle that people with incapacity should be able to make decisions and express wishes about their future care is very welcome and absolutely right.

1. I am concerned however, that the proposed legislation on advance refusal is misconstrued. I feel it is discriminatory to allow people to make advance refusals while denying them, as the proposed legislation does, the opportunity to make requests about treatments they may wish in the future. Why should we not allow someone to ask that if they develop dementia they do wish to be given appropriate drugs and care, and why should they not consent in advance to treatments, such as surgery (or even ECT) if they know about them and they would work for them?

2. As it stands the proposal to make advance refusals statutorily enforceable is likely to have grave effects on some of my patients. Very many of my patients accept and benefit from care which they may not have anticipated when they were well. It is the nature of being ill that one ends up in circumstances that are not anticipated. The choices people make when sick often change substantially from those they made when well.

In the obstetric field, birth plans have been widely used, but are routinely discarded in the heat of the labour ward. If they were legally enforceable they would most certainly cause death and disability in newborn children. Similarly advance refusals will cause unintended harm to some older people with incapacity.

It therefore seems to me that legislating to make advance refusal statutory rather than strongly advisory risks the welfare of patients. If they are to be included in legislation then advance requests should also be allowed. I would ask you to consider changing the wording of the clause on advance refusals to "is or is not" and changing the title to advance statements.

3. An enormous amount of the care I provide is given to people without capacity. If we have to fill in forms for each and every treatment, or consult attorneys who may not be close, we will be unable to do the amount of work we do now in the time available. There is already a grave shortage of Old Age Psychiatrists. In Scotland, the incapacity legislation has made dental treatment and flu jabs more difficult for those with incapacity and it was found necessary to make the incapacity arrangements "permissive" (something which can be used if felt needed) rather than obligatory (to be used for all procedures). I would strongly urge that you do this in this Bill too. If you do not, then older people will be denied treatments and will suffer as a result. It is therefore very important, under Section 6(1) that you ensure that the majority of care can still be provided under common law.

4. In the "best interests" definition, there is no component which talks about "Good Clinical Care". Surely what is good medicine and what will work and help is a key consideration in what is in a patient's best interests, surely "Good clinical care" should be added in here.

5. The clauses about testing the validity of advance refusals also need strengthening. Perhaps amendments such as:

1(b) add "clearly" to read "clearly applicable to the treatment"

4(c) add "clearly" to read "clearly understood or anticipated"

It is also very important that if doctors or others have "reasonable grounds to doubt" then they should not be bound by the directive.

The reason for these suggestions is, simply, that in my clinical experience, if these strengthened safeguards are not included in legislation, then patients will suffer and go untreated as a result. A good example would be a stroke patient who wrote a directive declining stroke rehabilitation, or a patient with a urine infection who wrote a directive declining treatments other than pain killers. The out turn of these statements will often not be death, but prolonged and enhanced suffering which could be easily averted. These statements need to be advisory therefore. Relatives, nurses and doctors should not be made to stand back and watch patients suffer as a result of a directive, which was not made with proper understanding of the situation in which the patients find themselves.

6. The powers of attorneys also need very good safeguards. We know that 10% of all financial attorneys commit fraud at present and we as clinicians find this very, very hard to sort out. With the current enduring powers of attorney, bankruptcy automatically disqualifies an attorney. We need clear statements in the legislation that where an attorney does not appear to be acting in the best interests of a patient, then he or she be displaced quickly and easily. Otherwise attorneys who do not have the best interests of their appointees at heart, will quickly be able to ensure neglect, under-treatment etc and we as clinicians will find it almost impossible to sort this out.

7. Finally, I am concerned about the powers of advance refusals. They should not be allowed to require the stopping of relatively simple treatments (such as anti-convulsants or diabetic medication). Otherwise, patients will again end up dying in desperate circumstances. Perhaps an extra clause could be added to section 10(4) to this effect.

I do hope these thoughts are helpful. I am very happy to discuss them further with the Committee if they so wish.

August 2003

16. Memorandum from the Medical Ethics Alliance (MIB 183)

The Medical Ethics Alliance is a Hippocratic and World Faiths coalition of medical bodies and individual doctors. We welcome the opportunity to comment on this draft Bill. We have been involved with some of these issues for a number of years having previously made submissions to the Lord Chancellor's Department.

GENERAL

1. We welcome the Bill's provisions to protect the financial and welfare needs of people who have lost, or never enjoyed the competence to be able to manage their affairs. We will not be addressing these areas.

2. We note that the Bill applies only to adults or those over 16 years. This is appropriate as proxy decision making for the protection of children is already provided for by other legislation such as The Children Act.

3. We recognise that there can be problems over decision making in health. We welcome the intention of the Bill to maximising the patient's ability to make their own decisions and exercise their competence fully.

4. Under present law health decisions can already be made on the basis of necessity or the patients best interests and there is a considerable body of case law on this.

5. The Bill proposes a number of relatively untried and untested proposals which may have unintended consequences. In Scotland, where the Incapacitated Adults (Scotland) Act has been in force, it has given rise to other problems. Health attorneys may disagree with doctors or cannot be located when needed. The replacement of the best interests principle has not always worked to the patient's advantage.

6. The bill does not define the "best interests" of a patient but merely suggests in section 4 that this could be something as subjective as a "belief" held under a lasting power of attorney. This is not good enough and is frankly dangerous. It vests a large amount of power with the donee but does not provide sufficient safeguards for the incompetent patient. Its potential for abuse in cases where health outcomes interlock with financial considerations is all too obvious.

We do not think that the "wishes and feelings" of patients alone should be taken into account. Values should also be included. It is probable that religious beliefs amongst those who regularly subscribe to a World Faith are likely to be part of their thinking. An example of this can be seen from the "Advance Christian Declaration for the Management of Serious Diseases" appended to this submission. It will be noted that it is more than an advance refusal of treatment. We think that such a document should be recognised and respected. As doctors we believe that our colleagues would welcome such expressions. Objective criteria of the best interests of a patient exclude the possibility that it could be in that person's best interests to have his or her life deliberately ended by an action or omission intended to end the life. To do so would be a denial of the inherent worth of the incapacitated patient. In the area of healthcare, "best interests" covers the restoration and maintenance of health, or of whatever degree of well-being can be achieved; the prolongation of life, and the control of symptoms when cure cannot be achieved.

Sections 23, 24, 25

7(a) This draft Bill would introduce some new powers into Statute Law such as advance directives. Some countries have found it necessary to put advance directives into a legally proscribed form. This helps in interpretation and avoids the danger of sweeping generalisations like "I am not to receive any life sustaining treatment if I suffer . . . pre senile dementia" (Voluntary Euthanasia Society). An advance directive, in our view should be at least as informed as ordinary consent to treatment. That written long ago and without informed knowledge could not come up even to the normal standard required of written consent to treatment. There will be problems of interpretation. Even testamentary wills are often disputed; one reason being the possibility that a person was acting under duress. This could apply to advance directives also. Being made in the past do they reflect the patients current views? They may well lead to delay, dispute and prevent good medical treatment being given. Since the controversial Bland judgement, tube feeding has been called "medical treatment" and therefore can be withdrawn or withheld. This bill if enacted would give force to advance decisions, including decisions to refuse "treatment" including food and fluids. This would therefore lead to the possibility of euthanasia by omission with statutory approval. It is not good enough to narrowly define euthanasia as "an active intervention to end life" the favoured definition of the Department of Health.

(b) The Bill does not meet the common situation of attempted suicide. A verbal or written statement may be discovered, possibly made at a time when the mind of the patient was disturbed. How should accident and emergency staff or ambulance staff respond when the patient has left a verbal or written instruction not to be treated? Non-treatment may result in suffering or an unpleasant death or adversely affect survivors resulting in permanent brain damage. Despite this problem being raised in a number of submissions to the Law Commission and Lord Chancellors Department and earlier parliamentary submissions, there is nothing in this Bill indicating that these everyday problems have been considered. We would like to see a specific clause dealing with suicide, and which is compatible with The Suicide Act and which takes into account the recent judgement of *HMG v Pretty* 2001.

(c) Medical advances that may be unknown to the patient may be excluded by an advance directive. There can also be unforeseen consequences from refusing treatment, for example an elderly person who refused "all operations", and who subsequently lost their competence. If they fractured a hip it would result in them becoming bedridden and possibly dying from infected bedsores, as in times past. Legislators rightly seeking to advance patient autonomy, need to be aware that a position which permits of no derogation could lead to suffering of the sort no reasonable person would have knowingly chosen for themselves. Indeed in the worse case scenario it could result in them being reduced to that very state that they most wanted to avoid.

(d) One of the greatest causes of anguish is unrelieved thirst. Unfortunately since the case of *Airedale NHS Trust v Anthony Bland* 1992 declared it to be lawful to remove the feeding tube from an insentient patient, there have been numerous such removals from the sentient and even the non dying to their great distress and the understandable concern of their relatives. We are aware of self-help groups who have built up dossiers of hundreds of such cases. It seems to us that the incorporation of Baroness Knight's Patient's Protection Bill into the Bill would avoid this danger.

8. Where sustenance is concerned, we argue that for those who are sentient and cannot swallow, there should be a presumption in favour of life. This presumption would yield only if medically assisted feeding was incapable of achieving its purpose, or was disproportionate or excessively burdensome in itself. We do not consider that it is possible or desirable to attempt to place a value on another's life such as to judge it not worth living. We are very aware that persons, even those with multiply disabilities, can have a happy life if their needs are met. Proof of this can be seen in numerous chronic care settings, hospices and the day to day life of the disabled in society.

Section 40

9. Disagreements over health decisions will inevitably arise either from the family or medical team. We would like to see an automatic right of publicly funded and timely appeal to a court of protection. We are not persuaded that the Bill as drafted provides for that, bearing in mind the imbalance between families and public authorities where in accordance with Article 6 of The Human Rights Act there is a requirement for equality of arms (ie equal representation).

Section 1, 30

10. The absence of a definition of competence in the Bill itself is a serious deficiency. There is much case law on this already and the Bill will also need to be consistent with other measures and laws concerning competence. Without a definition in the Bill it is not possible to judge the effects of the Bill. The absence of such a definition could result in powers being taken which are beyond those intended by Parliament.

In connection with this we do welcome the recognition in the Bill that competence may be both lost and recovered as a result in fluctuations in health.

Above all we wish to see a safe Bill and if the ethical and clinical problems mentioned above, cannot be resolved we would urge legislators not to enact that part of the Bill where existing case law is sufficient.

August 2003

17. Further memorandum from the Medical Ethics Alliance (MIB 1191)

Thank you for inviting the Medical Ethics Alliance to give oral evidence.

The Alliance was formed four years ago to promote discussion inside and outside the medical profession on medical ethics. It is a coalition of doctors from various faiths. It looks to the Declaration of Geneva 1948 of the World Medical Association following the Nuremberg trials. The Alliance studies contemporary medical ethical problems at conferences and through publications. We seek common ground amongst doctors of faith and Hippocratic inspiration. Some of the issues in the draft bill are of great concern to us.

The Alliance was formed after the publication of the BMA document "Withholding and Withdrawing Life-prolonging Medical Treatment" which laid down criteria for omitting food and fluids administered to stroke victims and others who were not dying and still sentient. This document has never been endorsed by the membership of the BMA. We believe that there should be a presumption in favour of the preservation of life and a humane duty to provide sustenance, if necessary with medical assistance to people with swallowing difficulties. This presumption would yield only if such assistance was unable to achieve its purpose or was excessively burdensome or disproportionate in itself or refused by a competent patient.

The lack of precise definition of "best interests" in the Bill is a serious omission. It can never be in the best interests of a patient to be killed but the scope which this Bill gives for withholding nutrition and hydration in the "best interests" of patients lacking capacity is deeply worrying. It is possible to harm or even kill patients by withholding what they need as well as by giving them what they don't need. We disagree with the narrow definition of euthanasia adopted by some as "a deliberate intervention undertaken with the express intention of ending a life". The observations made by many that this Bill could open the way to euthanasia by omission are unfortunately correct.

Another area of concern to us is the medical management of patients who attempt suicide. There would be major difficulties for medical staff in emergency departments if patients who are mentally ill refuse treatment by means of an advance directive. Not only would these difficulties be medico-legal but they could result in morbidity as well as mortality. Research has shown that most suicidal patients welcome their survival after appropriate treatment. We would respectfully direct the committee's attention to the Declaration of Bali of the World Medical Association, which called for the resuscitation of those who attempt suicide.

Thus we have severe reservations about advance directives. These rarely if ever come close to the standard of a contemporaneous consent or refusal of treatment. Noting that the Adults with Incapacity (Scotland) Act 2002 did not legislate for legally binding advance directives, we ask why such a controversial measure is included? The Draft Bill states that the document "Making Decisions" forms the foundations of this Bill. However "Making Decisions" considered that the issue of Advance Directives would not be taken forward in the light of the public's response. Would not this sensitive subject be best left to the courts as at present and as the House of Lords Select Committee on Medical Ethics recommended in 1994?

Another serious concern is the exercise of lasting powers of attorney or general authority without legal safeguards so that donees can override medical opinion unreasonably. Conflicts of interest will arise where inheritance is involved. We think this amounts to an exercise of power without accountability. We note at 16(4)(a) that a court-appointed deputy would have limited powers, but not so donees. We do not understand this. The Scottish Act provides for second medical opinions and the right of access to the Court of Sessions to resolve disputes. We think an effective and funded system of appeal should be included in the Bill.

We think 24(2)(b) and (c) are a recipe for muddle and betray little understanding of the working of busy acute medical facilities. At 30(6) we hope that anyone—donee or deputy—would have regard to the Lord Chancellor's code of practice which we are sure should put health benefits for patients first and not subjective considerations or legal process.

We welcome the intention of the Bill to preserve and enhance patients' and carers' welfare and freedom but encourage the committee to do this whilst safeguarding the vulnerable.

October 2003

18. Memorandum from the Church of England Community and Public Affairs Unit (MIB 561)

Draft Mental Incapacity Bill

INTRODUCTION

1. The terms of reference of the Church of England's Community and Public Affairs Unit require it to assist the Church in making a constructive and informed response to issues facing contemporary society. The Unit reports to the Archbishops' Council and, through it, to the General Synod.

2. The Community and Public Affairs Unit welcomes the consultation on the draft Mental Incapacity Bill, though it deeply regrets the brevity of the consultation period, and its timing to coincide with the summer recess.

3. This response is to question four: Are the proposals in the draft Bill workable and sufficient? and only in respect of healthcare at the end of life.

RESPONSE

4. No.

5. Clause 1(2) is most worrying in relation to healthcare at the end of life, because the distinction between permanent and temporary impairment or disturbance is crucial when a life or death decision has to be made.

6. Clause 23(2) is also worrying for failing to make a distinction between a clear, written directive about withholding or withdrawing treatment, and what may be no more than a vaguely expressed, and inadequately reported, general wish.

7. If it is established that loss of mental capacity is permanent, then clear, written advance directives to withhold or withdraw treatment should normally be respected. Few medical conditions are as clear-cut as the law might wish. It needs to be recognised that, as with ordinary wills, indolence and inertia can mean that even clear, written directives are not always up to date. There must still be room for medical judgement and scope for flexibility, therefore.

8. In the case of patients in the vegetative state the Royal College of Physicians advocates that patients should be observed for 12 months after head injury (traumatic brain injury) and six months after other causes, before the state is judged to be permanent. Only then should discussions of withholding or withdrawing treatment begin. Under current legislation the final decision has to come before the courts. The most important factor is time; the RCP guidance points out that there is no hurry to diagnose these patients and if there is any doubt, more time should be taken before a final decision is made. The Mental Incapacity Bill should require that sufficient time is given for an unhurried consideration of all the issues, so that the decisions made are as right as they can be. Guidance on the minimum time needed to establish permanent mental incapacity should be written into the Bill.

9. When loss of mental capacity is not judged to be permanent, there is no case for bringing a life-threatening advance decision into effect. The best interests of the person concerned must lie in the restoration of as much mental capacity as possible. Clauses 4(2) (a)-(b) refer to this and, if given due weight, could conflict with an advance decision were it not for the phrase "at that time" in Clause 23(1)(b). This is the point at which the failure to distinguish between permanent and temporary incapacity could open the door to euthanasia. While the conscious refusal of treatment is a right and does not of itself constitute euthanasia, the preliminary specification of conditions under which treatment would be refused might count as euthanasia if the condition was not a permanent one.

10. No one can fully know in advance how he or she will feel when a crisis occurs. Although opinion polls typically show that the general public is 80% in favour of voluntary euthanasia, only about 3% of the terminally ill favour it. The 80% figure implies that there is a widespread fear of the dying process, and lack

of confidence in the medical profession to manage that process well. Individuals should, therefore, be allowed the chance consciously to reconsider a decision if there is a reasonable likelihood of their being able to do so.

11. The opinion poll statistics may also be symptomatic of a society that dreads loss of personal control and the gratitude to others demanded by an unsought-for dependency on them. The 3% figure indicates that when it comes to it, these fears subside, or are subsumed under other concerns, perhaps such as the desire to journey well to death, to effect reconciliations, settle one's affairs, or just to "live until one dies" (Cecily Saunders).

12. Love is at the heart of the Christian message. The source of love is God and no created being is separated from that love. In human relationships Christian love always puts the well being of others above one's own. This paradigm of love undermines the perspective that personal, individual autonomy can trump other moral claims, such as the good of all, or the consciences of those involved in fulfilling a person's wishes. Human beings are, simultaneously, both individuals and in community, and moral decision making has to take this dynamic into account.

13. In summary, our overriding concerns are: with the failure of the Bill to distinguish between temporary and permanent mental incapacity; with its failure to distinguish between clear, written advance directives, and more vaguely expressed general wishes; and with its lack of a framework to allow for the sometimes messy and always unpredictable dynamic of human decision making at the end of life.

August 2003

19. Memorandum from Dr P J Howard (MIB 1187)

BACKGROUND

I have been a Consultant Physician with an interest in Gastroenterology for over 10 years. I have a particular interest in swallowing disorders and feeding problems both as a medical academic and as a Consultant Physician. I work closely in conjunction with speech therapists and radiologists to provide a clinical service for those with swallowing problems.

Swallowing difficulties in the immediate aftermath of strokes are not uncommon. The attendant risks of aspiration pneumonia in those patients who cannot swallow liquids is now known to be a significant cause of early mortality in these patients. Early swallowing assessments in stroke patients are now routine in general medical wards and stroke units. Fortunately such swallowing difficulties are transient and usually recover within the first few weeks after stroke. As a Gastroenterologist I am often asked to give advice regarding the management of such patients and to place gastroscopy feeding tubes (PEG tubes) in those with long-term feeding difficulties.

In this statement I shall be concentrating mainly on the implications of the Mental Incapacity Bill for the provision of hydration and nutrition for those who lack capacity. Nevertheless, I will also mention the implications of advance refusals on other aspects of patient care, in particular the resuscitation of patients who have taken drug overdoses and written "suicide notes" refusing resuscitation. I shall also mention the dangers of lasting powers of attorney which would leave patients injured by wrong decisions unable to claim compensation or damages since the attorneys (or court appointed deputies) do not have any statutory duty of care in the Bill.

IS FEEDING TREATMENT OR CARE?

Medical treatment is disease specific. The purpose of medical treatment is to prevent or treat disease and to alleviate pain and distress especially when cure is not possible. Palliative care is an established and respectable branch of medicine. Care refers to those things which are necessary in health and disease to sustain life. According to this definition the provision of hydration and nutrition, warmth, shelter, companionship, comfort and companionship would be care not treatment. Nutrition and hydration serve physiological function required to sustained life.

EFFECTS OF WITHDRAWAL OF HYDRATION

Failure to provide nutrition and hydration will cause the death. Starvation will lead to death over weeks or months. The effects of dehydration will lead to death in a much shorter period, usually within 10–14 days. Death through dehydration, if the patient is not imminently dying, is a particularly unpleasant and distressing way to die. Few, if any, patients would deliberately choose suicide through dehydration. The immediate effects of dehydration in a conscious subject include the development of intense thirst and a strong or even irresistible desire to drink, headache, listlessness, apathy and confusion progressing to delirium. As dehydration progresses the tissues shrink as they lose water, the skin becomes dry and wrinkled, the eyes sunken. With further water loss, blood volume falls and cardiac output declines with a decrease in the blood supply to the skin with the risk of pressure sores. Fever develops, probably because of disturbances in the temperature regulation in the brain, or because of super added infection in the by now

debilitated patient. Sweating ceases (which is one of the major means of heat loss) and body temperature may rise precipitously. If there is any doubt about how unpleasant and distressing death through dehydration is, one only has to go without fluids for 2–3 days, let alone 1–2 weeks. Few people in a Western climate have ever experienced real thirst, much less dehydration. It is only when patients no longer have access to water that they would experience dehydration in this country. Yet this is precisely what is anticipated in this Bill.

DEFINITION OF HYDRATION AND NUTRITION AS LIFE-SUSTAINING TREATMENT

The Mental Incapacity Bill defines “life-sustaining treatment” as treatment “which in the view of a person providing health care for P is necessary to sustain life.” (s 7(4)). Hydration and nutrition would therefore be medical treatment as they are “necessary to sustain life”. Moreover, donees of lasting power of Attorney (and presumably court appointed deputies) will have the power to refuse consent “to the carrying out or continuation of life-sustaining treatment” if the power of attorney “contains express provision to that effect” (s 10(2)). Hence, it is clear that the Bill if enacted intends that patients may direct the cessation of hydration and nutrition and also grant powers of attorney to the same ends.

I have yet to encounter a patient who wishes to die through dehydration and have never come across a deliberate suicide by dehydration.

BMA AND GMC GUIDANCE

Mention has already been made by several representatives of the Making Decisions Alliance of the BMA Guidance on withdrawing and withholding hydration and nutrition. This guidance specifically deals with treatment withdrawal, including the withholding of “artificial” hydration and nutrition from those who are not dying.

“2.1 the main focus of this guidance is decisions to withdraw or withhold life-prolonging treatment from patients who are likely to live for weeks, months, or possibly years, if treatment is provided but who, without treatment, will or may die earlier.”

Such treatment includes “artificial” nutrition and hydration but not the “offer of oral hydration and nutrition” (paragraph 3.3).

Hence in the common situation of swallowing difficulties arising from stroke, (which is usually transient and recovers within six weeks), there might be a ban on drip or tube feeding but not of oral feeding. However, oral feeding of such patients would risk choking to death or aspiration pneumonia. How can it be ethically proper to acquiesce to a patient’s refusal of tubes or drips while at the same time offering the patient oral food and drink which could kill him?

The BMA recognizes (as it should) that the deliberate withdrawal of hydration will result in a patient’s death but argues that it may still be withdrawn if the doctor feels that hydration is no longer “a benefit”. This implies logically that life is no longer a benefit to the patient.

“19.1 Although the health care team may foresee that withholding or withdrawing life-prolonging treatment will result in the patient’s death, this is fundamentally different from action taken with the purpose or objective of ending the patient’s life.”

I cannot think of any circumstances where I may ethically withdraw hydration from a non-dying patient, knowing that this intervention will cause the patient’s death in 10–14 days. The logical inconsistency of acknowledging that “withholding or withdrawing life-prolonging treatment will result in the patient’s death” on the one hand, whilst arguing that this is “different from action taken with the purpose or objective of ending the patient’s life” is remarkable. In the case of Tony Bland, the acknowledged purpose of withdrawing hydration was to bring about his death. The problem was precisely that Tony Bland would not die, but could go on living for months or even years, unless his fluids were stopped.

The BMA acknowledges that if doctors are to withhold hydration certain “safeguards” are required.

“19.3 Decisions to withhold or withdraw artificial nutrition and hydration from patients whose imminent death is not inevitable and whose wishes are not known, require additional safeguards which are discussed in Part 3D”.

At 20.1 the BMA states that “it accepts that many people perceive there to be an important distinction between this and other treatments” and that . . . “decisions to withhold and withdraw artificial nutrition and hydration are taken only in the most extreme cases, where its provision would not provide a net benefit to the patient”. However, later the BMA recognizes that the withdrawal of nutrition and hydration might be decided by general practitioners in the community for common conditions (such as stroke).

“22.1 (a) All proposals to withhold or withdraw artificial nutrition and hydration whether in hospital or in the community should be subject to formal clinical review by a senior clinician who has experience of the condition from which the patient is suffering who is not part of the treating team . . . for common conditions, the senior clinical could be a general practitioner, particularly where the patient is being treated in the community, such as in a nursing home.”

It is clear therefore that the BMA at least recognizes that the withdrawal of hydration and nutrition with the aim of causing death will be commonplace in hospitals and the community. In the preceding paragraph 22.1 it acknowledges again that “The withholding or withdrawing of artificial nutrition and hydration will inevitably result in the patient’s death.” There is a clear intention of the BMA to support decisions to withdraw hydration and nutrition from patients who are not in PVS without the sanction of the court.

“21.1 The BMA can see no reason to differentiate between decisions for patients in PVS and those for patients with other serious conditions where artificial nutrition and hydration is not considered to be a benefit, which are currently governed by established practice without the need for legal review.”

It is perhaps not surprising that the BMA also recognizes a right of conscientious objection to those (such as myself) who would object to causing a patient to die of dehydration.

“24.1 Where a member of the health care team has a conscientious objection to withholding or withdrawing life-prolonging treatment, he or she should, wherever possible, be permitted to hand over care of the patient to a colleague. This is a best practice which may also now be necessitated by the guarantee of freedom of conscience in Article 9 of the European Convention.”

It is also not surprising that the BMA recognizes the strain that such policies would place on staff and the need for “support”.

“26.1 Although not responsible for making the decision to withhold or withdraw treatment, those close to the patient are often left with feelings of guilt and anxiety in addition to their bereavement. It is important that the family are supported both before and after the decision has been made to withdraw or withhold life-prolonging treatment.”

“26.2 The emotional and psychological burden on staff involved in the withdrawing and withholding of life-prolonging treatment should be recognized and adequate support mechanisms need to be available and easily accessible before, during and after the decisions have been made.”

If the BMA recognizes such stresses amongst staff making these decisions, how much more stressful would it be for Attorneys or court appointed deputies if they were making these life and death decisions, as proposed by the Mental Incapacity Bill. The BMA recognizes that “Where the patient has died following a decision to withhold or withdraw life-prolonging treatment, however, the usual bereavement may be exacerbated by feelings of guilt or anxiety about whether the right decision was made and about the family’s role in that decision”.

GMC GUIDANCE ON WITHHOLDING AND WITHDRAWING TREATMENT

The GMC Guidance is an improvement on that of the BMA but it still acknowledges that hydration and nutrition might be withdrawn from patients who are not dying in paragraphs 38 and 81.

Paragraph 38: Always consult a clinician with relevant experience ... in cases where ... you are considering withholding or withdrawing artificial nutrition or hydration from a patient who is not imminently dying, although in a very serious condition, and whose views cannot be determined (see paragraph 81 below).

Para 81: “Where death is not imminent, it usually will be appropriate to provide artificial nutrition or hydration. However, circumstances may arise where you judge that a patient’s condition is so severe, and the prognosis so poor that providing artificial nutrition or hydration may cause suffering, or be too burdensome in relation to the possible benefits.”

In the July minutes of the GMC Council (which can be seen on the GMC website) it was acknowledged that there are issues relating to the legality and ethical standing of the GMC Guidance on Withholding and Withdrawing Treatment.

“Our guidance was prepared with the assistance of the Official Solicitor and a professor of medical law. It was the product of lengthy and detailed consultation and careful consideration of statute and common law. No significant concerns about compatibility with ECHR were identified during the drafting or consultation process. We did not therefore seek Counsel’s opinion on the guidance. However, the implications of the ECHR are developing as cases come to court as the result of the Human Rights Act 1998. In the light of these developments, and the opinion from Richard Gordon QC now in the House of Lords library, we are now considering whether to seek an opinion from leading Counsel, to provide further advice on the human rights implications and an authoritative opinion to which we may be able to refer if further public comments are made about the lawfulness of our guidance.”

In his advice Richard Gordon argues that—

“The GMC Guidance envisages situations in which although a patient’s death is not imminent life prolonging treatment may be withdrawn. There is no suggestion in the guidance that this may violate Articles 6, 2, 3 or 8 (see above). Further, even the existing domestic ECHR case-law does not go so far. The Guidance is, therefore, materially misleading”.

"I consider that the provision of hydration in such cases is likely to fall within the scope of the State's positive obligations under Article 2 ECHR. Failure even to advise clinicians of the importance of compliance with the principles set out in existing case law and with the separate obligations under Articles 6, 3 and 8 ECHR renders, in my opinion, this Guidance—in this respect—unlawful".

He recognises however, that even the GMC at least doubts the legality of its own advice—

"Note, for example, paragraph 17.4 of that Guidance which is ostensibly in direct conflict with paragraphs 38 and 81 of the GMC Guidance providing (materially) as it does that:

"Except where the patient's imminent death is inevitable, a decision to withhold or withdraw all treatment is likely to be inappropriate and potentially unlawful . . ."

CONCLUSION

The Mental Incapacity Bill would permit an extension of the House of Lords decision in *Bland* [1993] to patients who are not in PVS and to whom a duty of care remains. Such decisions would not be subject to judicial review but rather could be made by an attorney (or court appointed deputy). The state would be failing in its duty to positively safeguard life under Article 2 of the ECHR. Deliberate dehydration of a conscious patient so as to bring about death would also constitute inhuman and degrading treatment, and therefore be likely to offend Article 3. The abhorrent nature of such a practice would also offend the consciences of doctors and nurses (Article 9).

My position is that the family and attorneys should never be either permitted or required by law to make such decisions and that doctors must never be criminalised for providing patients with hydration and nutrition, howsoever delivered. The proposed Bill would legally require doctors and nurses to withdraw hydration from patients, knowing that this will inevitably cause the death of the patient. Continuance of feeding without the agreement of the attorney would be regarded as assault or battery since the attorney (or deputy) would "stand in the shoes of the patient" and have executive decision-making rights which would be legally binding on the doctor.

ADVANCE DIRECTIVES

There are real dangers in enshrining advance refusals of treatment in statute law. Patients' views, wishes and decisions are not necessarily fixed but may vary over time. Consent to treatment is often a process rather than an event and patients may come to accept treatment which they had previously refused and vice versa. Difficult decisions, in particular, may require serious deliberation over time and patients may change their mind about treatment. Few surgeons would accept consent to major surgery made months or years in advance. Unless advance decisions are frequently reviewed, they cannot be guaranteed to represent the contemporaneous wishes of patients. An example of this is the refusal of blood transfusions by Jehovah's Witnesses which must be reaffirmed annually. Few advance refusals of treatment are as vigorous as this. The Bill would allow not only written, but also oral, advance refusals even if expressed in "broad terms or non-scientific language".

Particular anxieties for doctors and nurses would arise in the case of suicidally motivated advance refusals or where the refusal was for basic medical and nursing care or the provision of hydration and nutrition, however administered.

Would the refusal of resuscitation in a suicide note constitute a valid and applicable advance directive? Would it become illegal to stem the hemorrhage of someone who had slashed their wrists?

Drug overdose is one of the most common medical emergencies. However, the Bill would prevent doctors from treating such patients if they had expressed a wish not to be resuscitated either in writing or orally. The criteria for validity are negative (s 24 (1) namely that P has expressed an advance decision which has not been withdrawn, is not contravened by a lasting power of attorney created subsequently and P has not acted in a way that is inconsistent with the advance decision. The three criteria for applicability (again expressed negatively) would clearly apply since the treatment is specifically indicated, the anticipated circumstances have arisen and are as foreseen in the suicide note.

However, we know as clinicians that the overwhelming majority of those who take overdoses do not have a suicidal intention and are pleased to be alive the next day. The term "parasuicide" is used for such cases. Nevertheless, this can only be known with certainty retrospectively after the patient has been successfully resuscitated. The case of suicide notes in cases of deliberate self harm or drug overdose, illustrate the difficulties of enshrining advance refusals of treatment in statute law. The current state of the common law regarding advance statements was carefully and sensibly set out by Mr Justice Hughes in the case of *Re AK* in which he pointed out that it was important to "ensure that such anticipatory declarations of wishes still represent the wishes of the patient. Care must be taken to investigate how long ago the expression of wishes was made. Care must be taken to investigate with what knowledge the expression of wishes was made. All the circumstances in which the expression of wishes was given will of course have to be investigated." *Re AK* (High Court of Justice, Family Division: *Hughes J* (2000) 58 B.M.L.R. 151; [2001] 1 FLR 129). It is my view that the law regarding advance statements should continue to evolve through common law rather than be enshrined in statute.

Further difficulties would arise for doctors and nurses in the case of patients using Advance Refusals of treatment to bring about “passive” euthanasia through the withdrawal of life-sustaining treatment such as insulin or through the withholding or withdrawing of hydration and nutrition.

LASTING POWERS OF ATTORNEY

Anyone making medical treatment decisions must be responsible for the consequences of those decisions. Doctors and nurses can be held to account through clinical negligence. A patient may suffer the consequences of a wrong decision himself. However, the Bill does not impose a duty of care on the attorney (or court appointed deputies). There is therefore no redress or compensation for a wrong medical decision made by a proxy. The only sanction is in cases of ill-treatment or willful neglect punishable by imprisonment for not more than two years or a fine. Ill-treatment or willful neglect are too high a threshold. Unlike the Adults with Incapacity (Scotland) Act 2000, which provides a second medical opinion procedure to tackle disputes between doctors and proxies before recourse to the Court of Session, there is no such provisions in the Bill. Disputes will inevitably arise between healthcare professionals and proxy decision makers who refuse the recommended treatment. Particular difficulties will arise when basic care, palliation or the provision of hydration and nutrition is refused. An attorney might also refuse resuscitation in the case of drug overdoses or deliberate self-harm.

Whilst carers and relatives ought to be involved in decision-making and should be consulted, executive powers for medical decision making ought to remain with doctors who remain accountable and liable for wrong diagnosis, advice and treatment. Without indemnity for negligence, any patient who is harmed through malpractice cannot receive compensation.

“BEST INTERESTS”

The definition of “best interests” in the Bill does not specifically mention “clinical” best interests which was the basis of the judgment in *Re F* 1989. According to the common law principle of necessity, treatment can be given on the basis of necessity in order to preserve life, prevent a deterioration in health and to alleviate suffering. Patients will take into account, not only clinical opinions regarding their condition, but also other non-clinical factors eg subjective, financial and religious considerations in making decisions regarding treatment. Doctors are competent to make decisions regarding a patient’s medical condition and the risks, benefits and alternatives of any proposed treatment. They are not professionally qualified to take into account these other factors in determining what is “best” for a patient. Nevertheless in the case of incapacitated persons it is good practice to take into account these additional aspects in so far as they can be ascertained.

SUMMARY

The Mental Incapacity Bill, as currently drafted, would enable attorneys, or court appointed managers, to refuse medical treatment, including palliative care and even the provision of nutrition and hydration, howsoever administered. Article 2 of the European Convention on Human Rights states that no-one shall be deprived of life intentionally. It must remain unlawful to bring about the death of a patient through neglect of basic care and in particular throughout the withholding or withdrawing of food or fluids. No patient should ever die, or be caused to die, through dehydration.

The proposed legal basis of decision-making is that it should be in accord with the patient’s “best interests” that it should be made on the basis of “best interests” however, “best interests” does not include “clinical” best interests. Deciding treatment for the incapacitated, doctors should consider first the clinical needs of the patient and then also the would-be wishes of the patient in so far as these can be ascertained by relatives and carers. The responsibility for the ultimate decision should rest with the doctor, who may nevertheless be held to account for failing to take into proper account the wishes of the patient, family and carers who are also responsible for the patient’s well-being.

RECOMMENDATIONS

1. Advance Directives should be taken into account in deciding the treatment for the incapacitated. Nevertheless they should not be legally binding on doctors who should retain responsibility (and liability) for the decisions they make.

2. Attorneys should not be given the legal powers to determine treatment. This again should remain with doctors who remain responsible and accountable for the care given to the patient according to their well established duty of care. If attorneys were to have the final say in treatment, they should have a statutory duty of care, be accountable for “negligent” decisions and liable for damages if the patient is harmed.

Witnesses: **Archbishop Peter Smith**, Catholic Bishops' Conference of England and Wales; **Dr Helen Watt**, Linacre Centre for Healthcare Ethics; **Dr Philip Howard** and **Dr Adrian Treloar**, Guild of Catholic Doctors; **Dr Gregory Gardner**, **Dr Gillian Craig**, Consultant Geriatrician and **Dr Jafer Quereschi**, Medical Ethics Alliance; **Lord Habgood**, a Member of the House of Lords, **Mrs Claire Foster**, Church of England Archbishops' Council, and **Mr James Bogle**, Lawyer, Catholic Union, examined.

Q379 Chairman: I think you heard all the housekeeping notices that I gave at the beginning. Could you introduce yourselves, please?

Dr Gardner: I am Gregory Gardner. I am the vice-chairman of the Medical Ethics Alliance which is a coalition of doctors representing different faith groups and Hippocratic tradition doctors. I have with me Dr Gillian Craig, who is a consultant geriatrician and an expert on issues regarding hydration of the elderly and Dr Quereschi, a consultant psychiatrist who is also an expert on suicide and the care of patients who have depression and suicidal inclinations. I am a GP and so I would be very happy to take questions on some of the general aspects of the matter.

Archbishop Smith: My name is Peter Smith. I am the Roman Catholic Archbishop of Cardiff and chairman of the Bishops' Conference Department for Christian citizenship and responsibility. I have brought with me Dr Helen Watt who is director of the Linacre Centre for Healthcare Ethics.

Lord Habgood: I am John Habgood. I am a retired Archbishop of York. I have a certain interest in this as I was a member of the House of Lords Select Committee on medical ethics which has I think set your agenda. I have brought with me Claire Foster who is the secretary who deals with these things for the Church of England.

Dr Howard: I am Dr Philip Howard. I am here on behalf of the Guild of Catholic Doctors. With me is Dr Adrian Treloar, also of the Guild, and Mr James Bogle, who is a representative of the Catholic Union. I am a consultant physician with a particular interest in patients with swallowing disorders and feeding problems.

Q380 Chairman: Best interest is a very important subject. Would the inclusion of a legal definition of best interests help clarify the legislative intent of the Draft Bill or would such a definition be unduly static and inflexible for decision-makers? How should the individual's clinical best interests be balanced against their wider interests?

Lord Habgood: It is clear from what was said in the last session that we are in an area where nothing is certain. Therefore, it seems to me to be very stupid to define something as vague as best interests. One can have certain guidelines. For example, one can say the things which are necessary to do in order to keep a patient comfortable and produce what improvement might be possible and so on and those are the long term best interests.

Q381 Chairman: This is central to the Bill.

Lord Habgood: It is indeed. It is a Bill that is having to deal with imponderables.

Archbishop Smith: Could I just add to that, I think one of the elements we would like to see—and I agree with Lord Habgood—it is going to be very difficult to get a legal definition that does not hamstring everybody. What should be included in the

understanding of best interests is the health interest of the person who is incapacitated, because that is a crucial issue, we heard very much in the previous evidence from Baroness Finlay. That needs to go in there somewhere and the essential element of what are the best interests of the person concerned.

Q382 Chairman: Under common law a doctor can meet the problem by showing that he or she is acting in the patients' best interests. Does this Bill not just add to that, it does not replace it, does it?

Archbishop Smith: The problem is that if you have an advanced decision it seems to me that a lay person, an advocate, or whatever, can override a doctor's proper professional, clinical decision. That is a crucial difficulty we would have with the Bill as it is drafted.

Q383 Chairman: I understand that.

Dr Howard: Speaking as a clinician the definition of best interests must include the clinical needs of the patient. In making a medical decision we have to decide what are the circumstances, what is the diagnosis and what is the range of options available to the patient. In other words what is their clinical need? The second stage of the process is deciding what ought to be done for the patient. That is a matter of patient choice. We must not confuse what the patient needs in a clinical sense with what the patient chooses. We all know that sometimes patients do choose not to take proper medical advice. It is perfectly possible for a patient who is of sound mind not to act in his own best clinical interests. If that is true of the competent patient how much more true must it be of an attorney. They too could act contrary to the clinical best interests of the patient.

Q384 Chairman: Would the professional be protected by this Bill if in fact that patient decided not to take the medication even though they knew it was in their best interest?

Dr Howard: The wishes of the patient or the wishes of the attorney, as I understand it, would trump that. If the patient is competent, yes. I think the issue is if the patient is not competent.

Dr Gardner: I would agree that the concept of best interests is open to misinterpretation and mischief. I would be very concerned that any kind of definition of best interests that feed away from clinical best interests could easily be misused. I think the legal definition by Lord Brandon about clinical best interests is a good working definition of clinical best interests, "treatment is in the best interests of the patient only if it is carried out in order to save their life or to insure improvement or prevent deterioration in their physical or mental health". We have had cases where it has been deemed in the best interests of patients to be starved or dehydrated to death. This can never be in the best interests of a

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patient. Leaving this clause of best interests in the Bill in a vague, ill-defined way is going to be open to abuse and misused and should be thrown out.

Q385 Chairman: We have had evidence from the Making Decisions Alliance who represent MIND and the Alzheimer's Society and others and they welcomed the Bill and the fact that best interests is included, does that surprise you?

Lord Habgood: May I come at that again, it seems to me when you are faced with the difficulty of making a definition quite often you can manage to define the process. It seems to me that in these difficult cases it is very hard to expect one person, a doctor, to make a decision. The concept of team-working involving the people who have care at various levels of the person in question offers some safeguard against an individual's notion of what best interests might be.

Q386 Chairman: Are you more concerned about the process than the principle?

Lord Habgood: The process would then need to have a clinical team making a decision in these difficult cases about what should happen rather than a decision made by an individual on the basis of a clear definition.

Q387 Lord Rix: Would it be possible in the current draft Bill to ensure that if a clinical decision was taken by a medical team it could override advance decisions? If that is not the case, how would you see it being made possible? In other words, say I have written that I only want to be kept comfortable and free from pain but I do not want to be kept alive artificially, could you override that?

Dr Howard: I think the Bill would mean that you could not override it. One of the problems I think of having legally binding advance directives is that they are legal instruments. Providing at the time that it was made the patient was of sound mind, they were not under undue duress—we have already heard what the difficulty in establishing that can be—and they knew even in “broad terms not scientific language”, to quote the Bill, what they were about then their wishes would be frozen in that document and the doctors would have to abide by it. One of the problems that I would have as an acute admitting physician is the issue of whether a suicide note for example would be a valid advance directive. I have looked at the clauses of the Bill and I have decided that yes it would be according to the Bill. We all know that many, many hundreds of young woman in particular, do take drug overdoses. It is a very common medical emergency. Baroness Finlay mentioned the question of Paracetamol overdose. Two years ago I had exactly the same problem, and my patient also went on for a transplant. What is the doctor to do if the patient is not incapacitated but merely distressed because of life circumstances? They may have discussed it with friends and relatives, may have written down their request in the form of a suicide note and gone on to take the overdose. We know that the majority of such patients, 19 out of 20, live but regret having taken

the overdose. Any clinician will tell you, any psychiatrist will tell you that this business of taking overdoses is part of the very natural history of how distressed and depressed individuals behave. They want out. They want to get out of the situation into a different environment and there are all sorts of feelings of guilt and concern about it. I know from my clinical experience that the next day many of these patients are glad to be alive. It would be a tragedy if suicide notes were deemed valid advance directives. Why do we treat them? For the reasons I have stated. We know that their views are not fixed. Indeed this is part and parcel of the way that distressed individuals behave. They want help, they want a different environment and they want to be surrounded by people who can help them. We know that but at the time that they take the overdose on the Friday or Saturday night their intention may very well have been to kill themselves and they may have thought about that for two or three weeks or even months. I think there are dangers in having advance directives which will freeze in time individuals' so-called wishes when we know in practice that they change over time. Baroness Finlay has told us in eloquent detail how when you are ill and you actually suffer the effects of disease you adapt to your circumstances. We are all quite clear as clinicians how much individuals respond to their circumstances. The resilience of our patients is really quite extraordinary when they are actually faced with difficult situations. I think there are very great dangers in fossilising patients' wishes in legally binding advance directives.

Q388 Mr Burstow: Can I go back to the issue of best interests, that is an issue that we need to explore in a lot more detail and put to you something that has been put to us in submissions from the British Psychological Society about best interests and needing to take into account the importance of the psycho-social aspect of a person's life. Do you agree with that contention and if you do are you putting forward an argument which is there is almost a hierarchy of best interests one works through and if you are putting forward a hierarchy where do psycho social factors come in?

Dr Howard: Again I think there is a danger in answering that kind of question in any fixed way because we deal with a whole panoply of situations in clinical medicine. What we can do and what we must do as clinicians is to give our professional judgments as to what the clinical needs of the patient are. In deciding whether or not a patient is going to be able to withstand a particular form of treatment we must take other considerations into account such as their psychological profile. Any good physician is also going to take into account the wishes and the feelings of the relatives and the carers. There are on the one hand clinical issues that have to be decided. We have the competence to make those judgments. Often of course there is not a unitary solution to a particular medical situation. There is often a range of perfectly proper and appropriate treatments that can be offered to the patient. Any good clinician is

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going to present those to the carers and the family and certainly take into account the wishes of the carers, the family and even an attorney. I think that the attorney should certainly be consulted. However I think he should take the role of a statutory consultee, a patient advocate, if you like, but not make the decision on behalf of the patient.

Q389 Mr Burstow: An uncharitable interpretation of some of the material we have before us that has been submitted by Dr Howard would be that ultimately the proposition that you are putting to us is that we should trust the clinician. Is that a fair summary of the position you are putting forward?

Dr Howard: I think one has to trust the physician because the physician is going to deal with the patient, but there must be checks and balances. We have professional standards which are recognisable. We have limits beyond which our treatment can be regarded as ineffective or even negligent. What I am saying is that in medical decision-making it is not just a question of the clinical situation it also involves other issues of a non-clinical nature which a good clinician will also take into account. As a clinician one has to define what the clinical needs are first and foremost. There must also be a standard of care below which he should not fall. He must always provide basic care to the patient.

Archbishop Smith: Could I go back to this best interests matter, I think that my difficulty is that the Bill seems to describe best interests in purely subjective terms and it seems to equate best interests with autonomy. I do not think that is a proper way of doing it. We can all act freely but not always in our own best interests. Someone can go and drink gallons of scotch or whatever their favourite is and say "I am exercising my autonomy" but I do not think any reasonable person, certainly not a doctor, would say that you are acting in your best interests. I think while it is difficult to define legally what you mean by best interests there must be some element in that which brings into the equation the whole question of the person's interest in good health. We know older people very often refuse treatment initially because they are upset, and that came out from Baroness Finlay and again from Dr Howard. There is a classic case in the Old Testament of Elijah, who was being pursued by Jezebel and we got totally fed up, he was weary and went out and sat under a tree and said to the Lord, "take me, that is it, I am finished". He was expressing his wishes and feelings very clearly but the good Lord sent him angels and two good meals and off he trundled into the wilderness and restored himself, so to speak. I think it is a very crucial element but when you try to look at what do we mean by best interests and not to equate it simply to the fact that I can choose whatever I want.

Lord Habgood: One factor has been left out so far is whether the incapacity is permanent or temporary. It does seem to me that unless there is a clear distinction, insofar as one can make a clear distinction here, we forget that we are dealing with two quite different moral situations. Where you have

a case of permanent incapacity then somebody has got to make the decision and presumably this has to be the clinician or the clinical team. Where you are dealing with what is believed to be temporary incapacity then it seems to me that the question of best interests resolves itself into the question of how can we restore sufficient capacity so that the person can make decisions about their own life? It seems to me very odd that Clause 1(2) of the draft Bill says, "it does not matter whether the impairment or disturbance is permanent or temporary". To have that rubric right at the beginning of the Bill presumably categorising all of the rest of it seems to me to spell confusion from the very start. At the very least I would like to see that clause taken out and then specification in other parts of the Bill as to whether the difference between permanent and temporary incapacity makes a difference.

Q390 Chairman: The Bill is based on a functional approach of the capacity at the time the decision has to be taken, it does not matter whether the impairment is temporary because it is at that point in time.

Lord Habgood: It does, if you take Clause 23 (1)(b) which actually uses the phrase "at that time he lacks capacity". Supposing somebody who is temporary incapacitated has left an advance directive saying that they do not want treatment, and supposing that person might well recover and be able to make decisions for themselves, according to the Bill the advance directive could be brought into operation during what might turn out to be a temporary phase.

Q391 Baroness McIntosh of Hudnall: May I just ask Lord Habgood whether he might consider it could be differently interpreted, that somebody who temporarily lacks capacity as a result of illness or injury and may recover may be in need of treatment and it may indeed be proper to give that person treatment in order to restore capacity. On the whole it is unlikely that anybody is going to use an advance directive to direct people not to recover them from temporary incapacity. I understand the philosophical point that you are making but I wonder whether in terms of the real implications of the Bill and how it would be implemented such a situation would ever be likely to arise?

Lord Habgood: It could arise if we had Clause 24(5) in operation, where somebody can specify that they would refuse a certain type of treatment that might be in their case lifesaving.

Dr Craig: I would like to support what Archbishop Habgood is saying about the dangers of people who have fluctuating capacity who might have written an advanced directive. There was a very shocking article in the *British Medical Journal* last year entitled "When Doctors Might Kill Their Patients". One of the contributors—who was a member the Medical Ethics Committee, and I would like to say I have forgotten his name—showed an example of an elderly man who was beginning to lose his hearing and beginning to lose his vision and he came into hospital confused. The implication was that here is a

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situation where if you do not think that it is worth living under those circumstances the doctor might take it into his head not to treat that elderly man, with the result that he dies. I think that scenario could be repeated many times over in our hospitals who are under pressure, with bed blockers and some doctors who are not sympathetic to elderly, frail and disabled people. We live in a society that is very intolerant of disability, very intolerant of disability, and we must protect these people.

Chairman: We should move on to general authority.

Q392 Baroness Fookes: The general authority is pretty wide as it stands in relation to medical interventions, do you think the general authority should be restricted to the particular categories of medical intervention?

Dr Gardner: I think it should be restricted to professionals acting within their own field of expertise. I do not think that it is appropriate for non-clinicians to be making effectively clinical decisions, it is not appropriate for proxy decision-makers to be making decisions about what is in the best medical interests and to be able to override medical decisions in that way. That is very, very dangerous.

Q393 Baroness Fookes: Is that the view of all of you?

Mr Bogle: Can I say I am a barrister practising in this area of medical law specialising in subjects relating to mental capacity. This was an issue that arose when the matter was debated by the Scottish Parliament in their equivalent Bill, Adults with Mental Incapacity (Scotland) Act. In Scotland the law is slightly different because there was some confusion or doubt about what general authority there was. In my view here in England it is much less unclear, to put it in its positive form, it is clear. I am not quite sure if it is necessary to redefine the general authority. I note in the evidence given before the Committee by the Scottish Law Society they were concerned about the wideness of this particular section. In Section 6(1) it says, "it is lawful for any person to do an act when providing care for another person", it is not restricted to medical practitioners, it seems intended to include those who are running nursing homes, and so on. More particularly it is a pathway, I would suggest, as the widening out of best interests under section four is a pathway to extend best interests beyond clinical best interests to non-clinical quality of life criteria so that the framework of advance decisions and lasting attorneys can be made to work. In our submission lasting attorneys and advance decision, which we will come on to shortly, go too far in that they require this broad general authority and they require non-clinical criteria to be superadded to the existing clinical criteria.

Q394 Chairman: Is this to protect the situation? At the moment I am serving on a protection order as a best friend, I help somebody with dementia. I have no legal protection at all and I am taking decisions

on her care. The Bill is intended to give me legal protection by statute because at the moment I have to rely on the common law.

Mr Bogle: Indeed but it goes too far in so doing. In the same way we would say advance decisions and more particularly lasting attorneys and deputies—bear in mind that deputies will be appointed by a court not by the patient and are likely, as in the case of the Scottish Bill, to be a chief social worker and not a relative or a friend as in your situation. What, in our submission, would be better and would answer not only the queries that have been raised by the change in the law but would probably meet the agreement of most of the people who have been consulted is to have a framework of statutory consultees and/or patient advocates—a term which is now used quite often—rather than a very precisely defined term of attorney, and we will come to that in due course, because an attorney stands in the shoes of a person from whom they have that power of attorney. That is I would submit and suggest, not quite what is desired in these circumstances. What is desired is somebody who will be consulted and if they are not consulted there should be sanctions. To go beyond that you then have to have this very wide general authority.

Q395 Chairman: How would I be protected in the future under this Bill which I am not at the moment?

Mr Bogle: The problem is not the protection of yourself because you may or may not be protected under this Bill.

Q396 Chairman: I am, under 6(1).

Mr Bogle: You are taking a sledgehammer to crack a nut. You can be provided with protection in the circumstances that you are without having to broaden out the general authority or the best interests criteria to the extent that has been done in the current draft of the Bill. The reason that has been done is because if you are going to have an attorney making a decision standing in the shoes of a patient (and I have to query to what extent you can alienate a patient's autonomy to a third party, but I will come on to that) then in order to achieve that you have to widen out the general authority. If you restrict the scope of these proxies being consultees or patient advocates who must be consulted (on pain of sanctions against the health care workers failing to do so) but do not actually make the decisions (and bear in mind they could make clinically negligible decisions for which they would not then be responsible) then you would not have to widen out the general authority so far. In the circumstance that you adumbrate in my submission you would still be protected but you would not have taken a sledgehammer to crack the nut.

Q397 Baroness Fookes: I am far from clear on this, there are a whole range of medical interventions from the very minor to the very major are you suggesting that somebody who acts under general authority should not be permitted to allow a tooth to be taken out which is hurting the person who does

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not have capacity, or some other very minor intervention as opposed to something of very major significance like a heart transplant. I am not clear where you think the line should be drawn.

Mr Bogle: In my submission the line is drawn adequately by the current law save that there must be or needs to be certain improvements to address the kind of problems that Lord Chairman has adumbrated and also other problems, for example those adumbrated by someone who has given evidence to this Committee who had the care of a mentally ill patient. I think particularly parents who are not consulted adequately who are overridden by carers in a way that carers do not necessarily intend but because the parent have been insufficiently empowered and feel they have been left out. That is a very area different scenario to the one that I have pointed to. The feeling is that deputies under this Bill—and the power of the appointment deputies will exercised by the court—will be parents with mentally disabled or mentally handicapped children or adults under their care. Whereas the scope of Bill, particularly if we look at the Scottish experience, would appear to indicate that they are more likely to appoint social workers in those sort of circumstances, which may or may not be common, rather than parents or relatives. I would suggest this may be rather common in some circumstances. That is a very different scenario from one that those parents envisage. Again you are using a sledgehammer to crack a nut. You have under the existing law in the scenario you adumbrated, sufficient power, empowerment and protection so that the patients that you are concerned about will receive the treatment that they require because the doctor is required, whilst they are incapacitated under the existing law to treat that patient in their clinical best interest until, if it ever happens, they return to capacity. When they return to capacity they then have the general common law right that every patient has to refuse treatment for a good reason or for any reason. When they are incapacitated as the current law stands they must be treated in their best interests. In the scenario you adumbrated there is sufficient protection under existing laws. The position that has not been provided for is the one that the Lord Chairman points to and some organisations point to, that is where they have a mentally disabled or a mentally ill person in their care and they are not medically qualified—they are a relative or a parent—and they would like to feel they have more participation in the decision-making process. In my submission that could be done adequately with a system of statutory consultees and patient advocates. To use the system of attorneys is to go too far, it is going to give them the power to require treatments to be withdrawn by doctors. You then put doctors in an invidious position. They go into their wards and there, perhaps, sitting at the end of the bed is a person with power of attorney who can order them to withdraw treatment even though it could be clinically negligent to do. That is why I say this is taking sledgehammer to crack a nut.

Chairman: We have your submission but we only received it today, we have not had a chance to read it.

Q398 Mrs Humble: All of your answers have been concentrating on a medical model and references to the individual concerned in this Bill as being patients. The point surely is that there will be many circumstances where they are not patients and we are not talking about the medical model. The general authority applies to people who are making decisions on behalf of those who are deemed to lack capacity in settings other than a medical setting. For example I am not even talk about nursing homes, there are many people with very profound learning disabilities and indeed physical disabilities who are in their own homes, in the community, often in a supportive setting with carers going into look after them. The points that have been made to us about the general authority is that it is necessary to broaden it out to include all of those people because they are the people who are making day-to-day decisions, not to do with operations or tooth extraction but to do with basis decisions about the personal circumstances of that individual, about their social care needs, and also financial needs. Surely the general authority should be there to cover those very, very large numbers of individuals who are providing that support and making decisions for people who lack capacity to do it themselves?

Mr Bogle: At the risk of hogging the evidence, under the Enduring Powers of Attorney Act 1985 you already have the possibility for power to be given to somebody to act on behalf of the incapacitated person to make financial decisions.

Q399 Mrs Humble: Not social care decisions.

Mr Bogle: That is right. That is where the lacuna is. That is where the gap needs to be filled is. But this goes very much further than that and moves into the whole area of medical attorneys and medical proxy decision-makers rather than the situation you outline where I agree there is a lacuna and where very usefully there could be some change in the law to give a little bit more authority to those who currently act on behalf of a mentally incapacitated person other than making medical decisions. This goes very much further than that. My concern is, and I suspect some of the medical practitioners here are concerned about this too, is how that will impact on clinical practice and the delivery of health care services to patients and individuals in this country. It is taking a sledgehammer to crack a nut, as I have said. There needs to be a filling in of the gap, if you like, the lacuna without having to go to this extent. The whole ambit should be drawn in so that we do not end up with the unintended consequence that doctors are being obliged on pain of severe sanction to withdraw treatments that they know for clinical reasons should be given to their patients.

Q400 Mrs Humble: Would you recommend to us that rather than have general authority we have the Scottish system where there is the three different elements, there is the legal decision-making process,

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the health decision-making process and there is a third element, the social care process. Are you suggesting to us that we should be filling the gap by having a separate function, a separate way of making those decisions? If so how would that work in practice? One of the advantages of having a general authority is that it is not high bound by rules and regulations and having to seek advice from another authority because we are often talking about very day-to-day decisions, decisions that need to be made straightaway and are often not in themselves hugely important or have huge consequences but are nevertheless vital to that person's day-to-day existence.

Mr Bogle: I agree. The difficulty is that the law is rather a blunt instrument. Most of those activities are carried out currently without any intervention by the law and relatively rarely anything ends up in front of the court. In a sense although there is a lacuna and it ought to be filled one needs to be careful about using the blunt instrument of the statute to try and set up a framework for decisions that really, as you say, are day-to-day decisions that nobody is going to challenge.

Q401 Mrs Humble: Except there are often disagreements with family members and paid carers or statutory agencies, so it may not go to court but it can go through complaint procedures and cause a lot of aggravation.

Mr Bogle: Yes, and equally inevitably when we lawyers and judges get hold of it there will end up being rulings with wide-ranging consequences.

Lord Habgood: I read this with some bewilderment, who sets up this authority? Who decides that B is a suitable person is to do all these things? Who checks that B does not embezzle the patient's funds? Who decides which person may do these acts?

Q402 Chairman: It is a functional approach. If that happened you would decide that I should be the best friend on the protection order.

Lord Habgood: Who decides?

Q403 Chairman: I volunteered.

Lord Habgood: If I am mentally incapacitated—which I am beginning to feel I am—how do I tell you I want you to act on my behalf and spend my money?

Q404 Chairman: Then I have the protection of the law in this Bill.

Lord Habgood: How do I tell you? If I cannot do it who can?

Q405 Chairman: If are you completely incapacitated you will have a doctor or indeed a relative.

Lord Habgood: Should it not say in the Bill how such a person is designated?

Q406 Lord Rix: The draft Bill authorises unwise decision-making by making it clear that lack of wisdom does not mean lack of capacity. How do family carers and others reconcile the duty of care

with empowering decisions that are seriously or consistently unwise. You talked about teeth: Somebody may well have rotting teeth but they expressed a wish they do not want to go and have them out. I just want to know how the Bill could cope with that.

Mr Bogle: Going back to the point about how things are done in the Scotland, I presume you were not referring to the Adults with Incapacity (Scotland) Act you were referring to the general law in Scotland?

Q407 Mrs Humble: I was referring to the equivalent act in Scotland. We had a presentation from Scottish lawyers out how that worked and how they did not have the general authority but they had set up different organisations to do a similar job to the one that is outlined in the general authority. Not quite, there were differences and as a non-lawyer I would not put words into the mouths of the lawyers who sat in front of us.

Mr Bogle: There are some problems with the working of that Act in Scotland. I apprehend from reading some of the evidence that was the feeling among some of the lawyers from Scotland who gave evidence to you, and also particularly among the clinicians, non-lawyers, doctors. The problem is not so much how you protect people from unwise day-to-day decisions so much as straying into the whole area of medical decision-making. That is where it starts to get much more confusing and complicated rather than the kind of decision-making for mentally incapacitated, disabled or mentally ill persons that I suspect your Lordship is talking about. That is the area where the problems arise. If you have a power and give it to a third party or indeed if you allow a piece of paper, a legal instrument, which is what an advance decision would be if it were in writing (but of course this Bill does not require it to be in writing) then you have a situation where somebody and something can direct a person who is a medical practitioner, who is qualified in the area and is clinically able to deal with a particular patient, (it could be a psychiatrist, but it need not necessarily be), to do something that he knows is clinically negligent and yet he will be required to do it under pain of sanction. That is requiring something of a doctor that we should never really require. That is where the danger in giving this broad authority backed up through attorneys and advance directives, begins to create problems. Whilst I would agree with you and with Mrs Humble there is lacuna that needs to be filled in so filling it as widely as the Bill does we then run into an area where problems arise and doctors are then being told by the lasting attorney or advance directive that if you do not withdraw this treatment, if you do not stop the treatment, and I have the power to tell you to stop, because this Bill has given me that power, then you will be committing a serious disciplinary offence. Ten the doctor is obliged to do something that may well cause harm to the patient but which, at the end

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of the day, if he does not do, will result in a very severe sanction against him. That is what troubles me.

Q408 Lord Rix: How do you protect the carer? Suppose an unwise decision was taken by a person who was deemed to have capacity but, nevertheless, an unwise decision was taken and the carer says no and stops that decision being fulfilled. What protection is there for the carer so that he or she is not taken to court by a relative who thinks that the unwise decision should have been allowed?

Mr Bogle: My immediate response to that would be general law in relation to necessity. I imagine you are thinking of a circumstance where there is an argument over whether necessity applies.

Q409 Lord Rix: Yes.

Mr Bogle: That would be a matter ultimately for the court to determine of course and any doctor or carer exercising good faith as the law stands at the moment taking an action and exercising such discretion as they have in the clinical best interests of the patient so to act, as well as the general best interest. I do not think there will be any sanction against a person in the way that you envisage. There would however be such a sanction against the doctor if you put the very strong powers that are envisaged under this Bill into the hands of a person who is not clinically qualified.

Q410 Chairman: In the examples that you give of a doctor surely if the doctor had a moral or religious belief that said that he would not do that then you are protected, they will not be told to do something which is against their moral or religious belief.

Mr Bogle: I am glad you asked that question. I apprehend we have some members of the Muslim Doctors Federation. Yes, doctors would be obliged under this Bill as it stands. There is no "conscience" clause in the Bill. But equally one has to ask oneself, to what extent would the average doctor say I have a conscientious objection to delivering clinically negligent services to my patient? I am not sure that is necessarily a matter of value systems, belief-systems or faith so much as simply a matter of good clinical practice. All doctors whether they be Muslims, Jews, Christians or have no faith at all are going to say surely, are they not, that they do not want to deliver a clinically negligent service.

Q411 Baroness McIntosh of Hudnall: I am very confused by this argument for one reason, if I as a competent person decides that I am faced with the treatment which it would be clinically negligent of my medical adviser not to give me but nonetheless I decline to take it the medical adviser in that case is at no risk whatsoever of being held to account for not delivering that treatment. As I understand it, and I defer to our witness who is a lawyer, if somebody is given a power of attorney that power is given by the person who originally had the power and the donee therefore acts as if he or she were that person. I

cannot see why a doctor is at any greater risk in that situation than they would be if the patient were making the decision on his or her own behalf.

Mr Bogle: You have hit the nail on the head. The problem is that the original person making the decision has a perfect right to say, because of the principle of autonomy, I do not want this treatment but they will suffer the consequence, not the third party. In the case of exercising a power of attorney albeit appointed by the patient if the decision is clinically negligent the attorney will not suffer consequences, only the patient.

Q412 Baroness McIntosh of Hudnall: With great respect that is not the point that is being advanced to us, what is being advanced to us is that the doctor will suffer the consequences, which is a different matter.

Mr Bogle: The doctor will suffer the consequences for the following reasons. If the third party, the attorney, makes or requires a decision which he in good faith believes is right for the patient (and he will believe it is in the patient's best interests, or else, presumably, he would not be advancing it) and the decision is clinically negligent then the doctor is faced with a problem which is very different than if the patient himself asks. This is because a person who is not going to suffer the consequences and has no duty of care is requiring the doctor to do what is clinically negligent. In those circumstances if the doctor decides not to do that he will legally be deemed to oppose the consent of the patient exercised by an attorney. Consent having been withdrawn, the doctor in giving treatment he believes clinically necessary will then not only be committing what potentially is a disciplinary offence but technically what is also a criminal assault.

Chairman: We now move on to new decision-making mechanisms.

Q413 Jim Dowd: Before I move to questions four and five apropos of what was said earlier about best interests and people not knowing necessarily themselves, when my mother was in the latter stages of the breast cancer, to which she eventually succumbed, she was offered chemotherapy and backed by her medical advisers at Kings College Hospital to undertake the course. She was completely sane and competent and she declined. She did that in the full knowledge of the consequences because she did not think it was worth it, are you saying that she did not do that in her best interests? Is that the submission that was made earlier? Certainly Lord Habgood mentioned it.

Dr Watt: I think the Act was talking about the fact that best interests had to be given due weight. It is not that you always have to do what is in someone's clinical best interest, moreover sometimes the treatment would actually be burdensome. All we are asking is that clinical best interests be basically acknowledged so that when someone is trying to make somebody die by denying them treatment that

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that should be a criminal offence, and that they give them due weight. We are not saying that clinical best interests is negligible.

Q414 Jim Dowd: I do not share that. I am convinced, because we discussed it at the time, that she made that decision in her own best interests. You are trying to say there is another best interest that should have applied in making that decision.

Dr Watt: None of us are saying that decisions about something like chemotherapy, which is not suicidally motivated, made by a competent person should not hold. It is a different scenario if the patient is suicidally motivated and if they are refusing something in advance without being given the opportunity of being given information on that treatment which a competent person had and if they are refusing basic help, if they are refusing advanced pain relief and feeding, even by a tube, we would see that as different from refusing something with full medical knowledge and without a suicidal intervention.

Dr Treloar: I think it is undoubtedly the case that in the best interests of your mother in her judgment meant that she should not have treatment. There is no question that it is clinically right or in the clinical best interest at time you withhold treatment like that, I do not think any of us have a problem with that. If I might give you a slightly different example of a gentleman I looked after three years ago with severe dementia, he was very distressed, very agitated, very confused, dreadfully incapacitated and one would imagine, although he did not know this, that had he written an advance directive he would have said "I only want treatment to alleviate my mental condition and my distress", indeed that is what his son said to us. He said, "no medical treatment, treatment of a mental health nature to alleviate my father's distress, that is what I want". The point about good clinical care is that in that circumstance the reason he was like that was because he had a heart rhythm disturbance. I had to go back and talk to the son, who we gave, in effect, powers of attorney, to say, "we want to treat this person with cardiac medicine, simple oral medicine". Interestingly he was just flying out of the United Kingdom, he was going through passport control so if I had rung him fifteen minutes later he would have been on a plane and I could not have spoken to then. In this case where it was clear we had been giving good medical clinical care which led to the improvement and the alleviation of that person's symptoms which could not have been achieved otherwise. In best interests there really should be consideration of what is good care and what will help. The second and third are when we get into these complicated decisions, when we get into things like advance directives of course it is terribly helpful, as Baroness Finlay said, if draft directives give you guidance and it be can helpful. If they prevented me from treating that person as I think under current legislation they would the effect of that would not have been a problem for me but it would have been that the patient who would have suffered. I come

across a lot of examples in my work with severely demented people in the later stages of dementia where those kind of things occur. Happily we negotiated with the son and explained it to him and he said, "of course, please, go ahead". I would have to say that in our work with attorneys, particularly under the enduring powers of attorney which we currently have you know, as we do, that ten to fifteen per cent of those are subject to fraud. I can tell you as a clinician it is extraordinary difficult to get that sorted out when a decision-maker is not acting in the interests of a person, it is very difficult, you can sometimes manage it if they turnout to be bankrupt, beyond that it is very, very difficult. I think therefore with these decision making mechanisms we need very good safeguards and we need the ability to negotiate. As has been said repeatedly this afternoon, I know, advance directives which are absolutely binding would be disastrous for patients; we need to be able to negotiate around them.

Chairman: We have a problem of time because we should finish at 6 o'clock or soon after. What I would suggest is that Questions 4 to 7 deal with decision making and I think you could answer those in writing, because I am anxious to have your views on Questions 8 to 12 which are about advance decisions to refuse treatment which I know you wish to talk to us about.

Q415 Baroness McIntosh of Hudnall: There are two questions relating to advance decisions which I would like to ask. Firstly, whether advance refusals if they are built into statute, in your view, risk the welfare of patients, and I think you have already given us some indication of your views about that. If so, can you suggest how the draft Bill might be amended to avoid this? Can you also tell us whether you believe advance directives should be given in writing?

Lord Habgood: I see the Bill talks about advance decisions, whereas most of the members of the Committee have talked about advance directions which indeed was the phrase used by the original House of Lords Committee. I think it is a better phrase because "decisions" seems to imply, "This is the last stage of the process. You make your decision and that is it." A directive is a piece of advice given in circumstances which no doubt are quite different from those when it actually comes into effect, and that forms general advice as part of that material which the clinical team uses to make its decisions about the suitability of treatment. That seems to be the proper function of a directive. If it was made legally binding, it would take away from the clinical team the power of final decision and almost certainly result in patient harm. It seems to me important also that the advance directive should be in writing. It need not necessarily be in a very strict legal form, it is simply an expression of a wish.

Q416 Baroness McIntosh of Hudnall: Since the language of the Bill currently does refer to advance decisions, can I take it then that you would recommend the language of the Bill be changed to

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refer to “directive”, which would in your view have the effect of removing the absolute quality of that statement made in advance?

Lord Habgood: I would prefer directive because a directive is simply an instruction, it is not a final decision.

Dr Howard: I would agree with that. I think they should be advisory rather than mandatory and I do not think we should freeze somebody’s views in time. I have given the example of the suicide note which would be a very common problem. In reaching a decision, very often with regard to difficult decisions, it is a process over time rather than an event. Yet here we are almost treating a decision by a patient as something which is absolutely fixed. It is only fixed if the patient dies, they have the treatment or they become incapacitated. Very often patients will decide but will wish to discuss decisions and may even change their views many times over. In ordinary clinical practice, if for example you are going into hospital for a hip replacement, the surgeon is going to be very keen to make sure your consent is up-to-date. There is an argument to discuss the operation with the patient in out-patients. But that may be months beforehand, so always get contemporaneous consent.

Q417 Baroness McIntosh of Hudnall: But in people who lack capacity, by definition, that is not going to be possible.

Dr Howard: No, but the decision could be made months or even years in advance. I had a patient who, curiously enough, I had known before, who had made an advance decision unbeknown to me. It was actually stuck in his notes to the effect that if he became incapacitated and confused and was suffering from a terminal illness he would not want to be treated. I treated him, not knowing he had made that. His wife said I should not have treated him. It was clear he had quite advanced lung cancer but when I had treated him I asked him, “Did I do the right thing?” He said yes. What was curious in that case was when I came to talk to him about his lung cancer, it was quite clear both from what he said and from what his wife said, he had not really faced up to the possibility of his developing a malignant disease at all. In other words, he was just like any other patient. That decision was made—and his wife made an advance decision as well not to be treated under similar circumstances—I think as a result of a television programme when both of them were fit and well. They both decided hypothetically—in practice it was hypothetical—this is what they would want. But when it actually came to facing up to the reality of having lung cancer, he and his wife were just as anybody else. They had not really thought about the actual implications. They had not understood what it would mean to have a terminal illness.

Dr Craig: Can I give two examples very quickly?

Q418 Mr Burstow: Can I ask my question and then it might be usefully illustrated by the examples about to be given. It is really to try and understand the

nature of the concern and whether or not in fact on reading of the draft Bill the concern is being answered. In Clause 24(4) it lists (a) through (c) a series of circumstances in which the advance decision is not applicable. My reading of that, and I am not a lawyer, would suggest in almost all circumstances unless the person has had the ability to act as a time machine and go to the future and take detailed notes of every aspect of the circumstances surrounding their loss of capacity and the condition they are in, that an advance statement is not likely to be valid or, if not, entirely valid, and therefore is a material factor in the decision making process which would not be binding in that situation. I wonder if the witnesses we have here have looked at this and why, having considered it, you still come with the views you have been putting to us so far about this particular drafting of the Bill?

Dr Howard: Because they can be expressed in very broad terms and they may appear to be rather specific. For example, if I can give you another case, I think it was an American one. A gentleman stated that in the event of his becoming incapacitated and suffering a cardiac arrest, he would not want CPR (cardiopulmonary resuscitation). He had an inguinal hernia repair under general anaesthetic, he suffered a cardiac arrest. Question: should he be resuscitated?

Q419 Mr Burstow: Then (4)(c) under Clause 24 says, “An advance decision is not applicable to the treatment in question if circumstances exist which were not anticipated by P at the time of the advance decision and which would have affected his decision had he anticipated them.” Surely that scenario is directly addressed by that drafting?

Dr Howard: No, because it was a very broad one. He was incapacitated by virtue of being under anaesthetic and he had suffered a cardiac arrest. We, of course, in this country would resuscitate him immediately. But there is always a risk that he may suffer anoxic brain damage and therefore he was not resuscitated.

Q420 Mr Burstow: The point I am making is that we are talking about the precise drafting of the legislation, not the situation which arises out of the common law we currently have. The drafting I have just read to you surely provides a situation which was not anticipated and as a consequence this directive in that situation would not have been one which would have been binding.

Dr Craig: Could I come in on this one? Reading Clause 24 I was filled with horror because section (2) provides chaos and muddle. I really do not see how the Government can possibly argue that advance directives should be legally binding when there are so many situations which undermine their validity. In an emergency situation in casualty or an acute medical ward when a junior doctor is called to a crisis situation, he cannot decide whether Patient A’s advance directive is valid or not in all these various scenarios. It is just totally impractical. May I also point to the experience in America which shows that

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in fact legally binding advance directives do shorten life, they can be a death warrant, they can cause patients to die unnecessarily early. There was a paper I read a few years ago which showed that patients who had signed advance directives died earlier than those who had not. The Federal Government said, "Great, these are working", because their aim was to cut health care costs. The patients who had signed advance directives were dying of things like (inaudible) after successful hip operations, they were dying of coronaries because they were not resuscitated, and all this sort of thing. They are really dangerous. One final point, an example of when advance directives are dangerous and should be overridden: a consultant physician had a coronary and he survived initially and he told his junior doctor he was not to be resuscitated. He then had a cardiac arrest and he was resuscitated and this happened four times. That man is now enjoying a happy retirement and he is thankful that the junior doctor did override his wishes and he said to a colleague, "Do you know, that was the only occasion that young man ever gainsaid my wishes."

Q421 Baroness Knight of Collingtree: I wanted particularly to ask a question of Archbishop Smith, if I may. It deals with the Catholic Bishops' Conference Statement which has been presented to us. It actually started with the suggestion by the BMA, which has no force of law behind it at all, that giving food and drink is treatment. The Conference stated, "Existing case law already permits patients in a persistent vegetative state to have 'treatment' ... withheld with the aim of causing death." That is actually not true because, as I understand it, the Law Lords who made this decision made it perfectly clear it was not to be used as a ground rule, that it could be done to patients although in fact now we have scores and scores of cases on record where this is being done to patients. The Conference said, "The law has been left, in the words of one Law Lord, in a 'morally and intellectually misshapen state', and he was one of the Law Lords who was dealing with that particular *Bland* case". Then you go on to say, "The Draft Bill does nothing to reverse this unfortunate situation." Would you like to comment on this please?

Archbishop Smith: There is a difficulty with the *Bland* case, and I am not going to give all the details of it because it is complex. In the old days, if I can put it like that, medical people generally would talk about basic care, in other words, feeding, hydrating, washing and so on. What the *Bland* case appeared to do was to include that basic care as treatment and there was a confusion there, I think with respect to the Law Lords, because it is perfectly legitimate for me as person who is capable mentally and so on to refuse treatment which others may decide would be in my best interests, but if I decide, "This is too burdensome for me", it is perfectly morally and ethically acceptable to say, "That is my choice, even though I know as a consequence my life will be

shortened." The unethical part, we would say, is, "If I choose to do that with the specific intention of shortening my life." Does that help?

Q422 Baroness Knight of Collingtree: Yes, except I was more interested in those patients who do not wish to die and are in fact dying through this particular ruling. That is what I was trying to ask you, whether you think the draft Bill does address that point which, to me, seems grossly wrong?

Archbishop Smith: No, I do not think it does. This is one of our difficulties. I do not think it is clear enough in the Bill. There ought to be some cautionary element to say, "Even where somebody has got a lasting power of attorney or general authority, that person cannot act with the consequence of producing or leading that person to death." In other words, there must be some restriction on what can be permitted and what cannot.

Lord Habgood: This was a subject of great discussion on the Select Committee 10 years ago, and I think I was in a minority of one in saying that refusal of hydration and nutrition should not be regarded as equivalent to refusal of treatment; it was not a form of treatment, it was about basic care. In the *Bland* case, it was less undesirable because *Bland* had no cerebral cortex, no consciousness, and this was a quick way to let him die. If the refusal of food and drink takes place in somebody who is conscious, then it seems to me you are in a different ballgame altogether. To starve to death is not consistent with basic care, as I see it.

Lord Rix: I agree.

Baroness Knight of Collingtree: Thank you.

Q423 Mr Burstow: We have partly picked up on the other point I wanted to ask, which was this concern about how you deal with fluctuating capacity which was very much part of the Church of England's submission, and I think it has been picked up by other submissions as well. It would be useful to hear from any of the witnesses of any specific thoughts and suggestions they have about how to improve the Bill to ensure there are safeguards in respect of that.

Lord Habgood: Can I go back to the point I was making at the beginning, namely much depends upon prognosis and whether the incapacity is judged to be permanent or temporary. It seems to me that particular provisions of the Bill need to be written with that dichotomy in mind. If you have permanent incapacity, it seems to me it is permissible to take action through the various mechanisms proposed here. If you have temporary incapacity, it seems to me the aim must be to try to restore as much capacity as possible in order somebody can make decisions for themselves.

Dr Howard: It is very difficult because you are considering fluctuating capacity, and I think a number of us have said also "fluctuating decisions" even if you are capacitated. A lot of the problems with this would not arise if the issue of capacity did not trigger off the full effects of advance decision making and proxy decision making in a way which

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is going to bind the doctor. If advance decisions were indicative, as I think they ought to be, and if proxy decision makers were consultees, patient advocates, rather than people who were in the driving seat making the decisions, I think a lot of these problems would lessen.

Q424 Mr Burstow: You have made your views on that very, very clear today. I wonder if there were any other safeguards over and above those which you particularly want to be sure the Committee was mindful of in framing its report and recommendations in due course?

Dr Howard: I agree with Lord Habgood, in that in clinical situations what we always try to do is enhance the patient's capacity. That may well mean treating the medical conditions which are pre-disposing to incapacity, such as chest infections and so on.

Q425 Chairman: If an advocate is acting for somebody who is completely incapacitated and advises the decision, is that so different from an attorney in the same position?

Dr Howard: The attorney would actually be making the medical decision according to the Bill. An advocate or the consultee should be involved in the decision making process as a matter of good practice. I think this ought to be placed on a statutory basis. The attorney should be a statutory consultee, somebody who is recognised under statute law and ought to be consulted.

Chairman: The questions we have not reached you have actually answered because we have slightly wandered occasionally from the actual subject we were on. The only things we have not reached are the new decision making mechanisms, Questions 4 and 5, and you might like to write to us on them. I think we have your views now on basic care. If there is anything on lasting power of attorney, please write to us as well. We have reached the time to finish, thank you very much indeed, it has been a long afternoon. We have found it very, very helpful. With Baroness Finlay first and then yourselves, we have found it a very helpful afternoon. Thank you very much.

20. Supplementary memorandum from the Medical Ethics Alliance (MIB 1203)

BEST INTERESTS

1. Would the inclusion of a legal definition of "best interests" clarify the legislative intent of the Draft Bill or would such a definition be unduly static and inflexible for decision-makers?

The Joint Committee should ensure that the Draft Mental Incapacity Bill includes a clause that prohibits the withdrawal of food and fluid however delivered with the intention of shortening life. Food and fluid should not be withdrawn unless the means of provision is evidently burdensome to the patient. There should be no requirement that such provision should improve the condition of the patient since this may not be possible. Parliament must acknowledge that without nourishment and fluids all human beings will die. The criteria used to consider "best interests" are far too vague. Lord Brandon's "principle of necessity" should not be discarded. A treatment should be considered necessary "if, but only if it is carried out only to save their lives, or to ensure improvement or prevent deterioration in their physical or mental well being." (Ref: Re F 1990 2 AC1). See also *Northridge v Central Sydney Area Health Service* [2000 NSWSC 1241] 29 December 2000.

The Mental Incapacity Bill should comply with the Universal Declaration of Human Rights 1948, which forbids discrimination on the basis of personhood. Article 6 declares that "Everyone has the right to recognition of a person before the law." Please note that this applies to everyone—the old, the disabled, children with severe learning difficulties, those with brain damage—in fact all people whether they are deemed to be mentally incapacitated or not.

Parliament should note that many people with conditions that fall short of a permanent vegetative state are having life sustaining food and fluids withheld with fatal results. In some cases this amounts to euthanasia by omission. Elderly stroke patients who cannot swallow are at particular risk. The concept of "Best Interests" should be restricted to clinical best interests otherwise it can be open to misinterpretation and misuse. The best interests of the patient will invariably include the provision of basic care. (For definition of basic care see answer to question 13).

We are concerned that the law is proving a weak defence in practice. There can be no adequate legal definition of "best interests" that fails to recognise the right to life. Judges can be ill informed and prejudiced on matters of medicine and ethics.

2. How should the individual's clinical best interests be balanced against their wider interests?

There should never be a conflict between an individual's clinical best interests and their wider interests unless it is ever considered "this patient would be better off dead." This however is a philosophical value judgment that "this person's life is no longer worthwhile." The "best interests" of a patient are never to be killed by an act or an omission.

GENERAL AUTHORITY

3. In your view, should the General Authority be restricted to particular categories of medical interventions? If so, what restrictions would be appropriate?

Giving Lasting Power of Attorney to a proxy in medical decision-making is inappropriate. Since doctors frequently get diagnoses wrong the potential for proxy decision makers to make poor medical decisions is even greater. Making decisions "in good faith" will not ensure greater accuracy. According to evidence presented to the Scottish Parliament in 2000 the congruence between the views of patients and proxies is often minimal with some studies suggesting it is no greater than chance.

Social service departments in England and Wales are often financially involved in the care of patients in residential and nursing homes. From April 2004 we understand that they will be fined if patients awaiting placement in the community block hospital beds. Thus they may have a vested interest in the patient's early death. This being so, social workers should not be made court deputies and given powers of life and death within the terms of the Draft Mental Incapacity Bill. Parliament should also be aware that pressure of work and shortage of beds in the Health Service combine to make many doctors resentful of elderly bed blockers. This is exceedingly dangerous and may lead to inappropriate decisions to withhold life-prolonging measures including nutrition.

There are indications that the life expectancy of women may have decreased in the last four years in areas that have a high proportion of elderly people. This may be a consequence of publication of the BMA guidelines on Withholding and Withdrawing Life Prolonging Treatment 1999. This trend if confirmed requires further investigation. In the opinion of Richard Gordon QC, the Mental Incapacity Bill is incompatible with article 2, taken in conjunction with article 6 of the European Convention on Human Rights, because it fails to comply with the state's obligations under article 2 to provide practical and effective protection of the right to life.

NEW DECISION-MAKING MECHANISMS

4. Do the provisions contained within the Draft Bill enable people to be sure that their beliefs with regard to treatment will be respected if they lose capacity? No. The cards are stacked in favour of discontinuing treatment or sustenance. There is no provision in the act to make an advance directive in favour of continuing treatment or sustenance, only in stopping it. The refusal of treatment is given respect but request for nourishment does not seem to have the same respect afforded it at all.

5. Should the Draft Bill specify that a person acting on behalf of a person with incapacity should have regard to their values as well as their "wishes and feelings" when deciding what is in their best interests? There is a dangerous subjectivism involved in deciding what is in someone's "best interests". Values are important but evaluation of "best interests" should be made on objective criteria, not subjective ones. An important additional point is that the values of doctors and nurses should be respected. Health care professionals from any faith tradition, which abhors the deliberate taking of life—whether by action or omission—should have the right to protect their own consciences.

6. As in our society people choose to adhere to different values and beliefs, do you consider that the Draft Bill achieves the right balance between respect for individual diversity and respect for life? If not, what would you change? Respect for life is an elastic concept because it can be more or less. If respect for life diminishes to the point where a person's life is considered to be not worth living, then "respect for life" ceases to have meaning. The principle of the sanctity of life, which protects patients from killing by action or omission, is the only foundation on which to build an ethical framework strong enough to resist utilitarian pressures.

7. In your view does the Draft Bill distinguish between ending life by omission and not aiming to prolong life by inappropriate means? If not, what safeguards would you like to see? No it does not. It gives scope to ending life by omission. The bill should make it plain that food and nutrition is not medical treatment but part of basic care. Withdrawing this with the intention of killing the patient is always wrong, though it may be necessary occasionally to withdraw tube feeding for a time if it becomes burdensome to the patient (eg causing diarrhoea).

ADVANCE DECISIONS TO REFUSE TREATMENT

8. Will giving advance refusals a statutory basis risk the welfare of patients? If so, how might the Draft Bill be amended to avoid this?

Yes. Advance refusals have already been shown to risk the welfare of patients. They shouldn't be made legally binding.

9. Should the Draft Bill stipulate that advance decisions must be made in writing? Yes of course they should be made in writing. There may be no proof of verbal wishes and this can lead to disputes in court. Directives should be carefully considered decisions made with the fullest information although no matter how good the information is, it is impossible to foresee every circumstance. They should not be made under duress and be guidance only. Patient's wishes often change with changing circumstances. Some people have lived to be thankful that their death wishes were ignored.

10. In your view are the safeguards in the Draft Bill sufficient to protect individuals who suffer from fluctuating levels of capacity? The fact that "best interests" is not defined allows the possibility of the application of "futile care theory." This is a position adopted in the cases of Anthony Bland in 1993 and Mrs M and Ms H in 2000 where the patients' lives were considered to be not worth living. There are very few safeguards in the bill since the proposal to vest the power of life or death in the hands of an attorney doesn't seem to carry any accountability. There should always be a presumption in favour of life.

11. The Draft Bill puts into statute the current common law position as regards advance refusals. Would denying capable individuals the right to make statutorily enforceable advance decisions to refuse treatment amount to a form of discrimination against people who later become incapacitated? No. If anything it would be a safeguard. If advance refusals are made statutorily enforceable, an incapacitated patient might be at increased risk if their earlier wishes were inappropriate and ill advised because nobody could then protect them.

12. Do you envisage that there are any medical circumstances when the wishes expressed in a valid advance directive (or a person's wishes expressed through a donee acting under an LPA) might reasonably not be followed by the treating doctor? If so, can you give examples?

We are concerned about clause 24 which will cause considerable chaos and muddle. It is unreasonable to expect a busy doctor to ponder all the possible factors that could invalidate an advance directive. Examples might include the following circumstances:

- If the treatment proposed is not the treatment specified in the AD or where a different drug is proposed.
- If there is a change in medical circumstances. For example, new treatments for dementia, CJD, AIDS etc. Section 24(4) describes circumstances where new treatments develop which were not known or foreseen by the patient at the time they made an advance directive.
- If there is a change in prognosis. Patients diagnosed as suffering from a "Permanent Vegetative State" or other severe mental incapacity who may recover slowly over years. (See case 1 in annex).
- If there is a change in social circumstances when necessary support is given.
- If the patient had been suicidal or depressed when they made the AD.
- Where there is doubt over the wording of the document. The doctor might realise that the condition was eminently treatable with a good chance of cure or significant improvement.

BASIC CARE

13. Should the Draft Bill exclude "basic care" or a "minimal level of care" from its procedures and mechanisms? If so, how should "basic care" or a "minimal level of care" be defined?

Yes. That is most important. Basic care should be defined carefully. It includes:

- (a) Provision of food and water by any reasonable, appropriate and proportional means that do not cause the patient unacceptable discomfort.
- (b) Basic nursing care and bodily comfort provision.
- (c) Warmth, clean dry clothes and clean bedding.
- (d) Shelter and humane friendly support in safe surroundings.
- (e) Pain relief short of deliberately ending a life.

It should be emphasised that the provision of food and fluids via a tube is not "medical treatment." There is no illness or pathology being treated. The BMA Ethics Committee's guidelines have not been endorsed by the profession. The committee needs to be aware of the fact that a fully functioning cerebral cortex is not needed for the sensation of thirst. Most people would be shocked to know that the provision of food and fluids via a tube is now called medical treatment so that it can be withdrawn. If it is considered to be inhumane to starve or dehydrate and animal to death (by withholding basic care) then at least the same protection should apply to human beings whether mentally incapacitated or not.

LASTING POWERS OF ATTORNEY (LPAs)

14. Do all the witnesses agree with the Catholic Bishops' Conference view that the Draft Bill currently contains insufficient safeguards against donees who fail to carry out their responsibilities properly? If so, how should these safeguards be increased?

- (a) Too much power is proposed to be vested with donees. They should have an advisory capacity only.
- (b) Doctors and other health professionals must have prompt access to court to appeal against decisions. This implies access to good lawyers and properly funded legal aid.
- (c) Decisions should be monitored by an independent person.

15. Should Local Authorities be given duties to investigate possible abuse taking place under the provisions of the Bill? Would this approach help to address any concerns you might have about the exploitation of vulnerable people?

See answer to question 3 above relating to dangerous conflicts of interests with local authority social workers.

Annex

Case 1. From a nurse working in a centre in the Midlands specialising in the care of severe brain injured patients. Mr S, a 43 year old man who was admitted to us following extensive brain surgery was only able to blink and move a thumb. Three years later, after extensive rehabilitation he can walk, talk, eat small mouthfuls of diet, is continent and fully aware of his surroundings. He is glad he is alive now and when made aware of this new bill had this to say: "I disagree with it. No one has the right to make that decision. Everyone should be given the right to live. I always knew I was going to get better."

Case 2. Elderly lady who suffered a stroke. Starved for 48 days in a hospital in England. Doctors equivocated about a PEG. Relatives could not agree.

Case 3. Elderly woman. Teaching hospital, Scotland. DNR order made against the wishes of the son. Naso-gastric tube in situ. Given tap water only for seven weeks. Died. No inquest. Non-clinical "expert" advised the coroner that all was done "in the patient's best interests."

Case 4. 83 year old lady. Minor CVA. Swallowing impaired. No food or water given. Died day eight in residential home.

Case 5. Elderly lady. CVA. Not hydrated. Died day six in nursing home.

Case 6. Elderly man. Had drip but no food for six weeks in hospital. Too weak for a PEG. Could swallow but not being fed. Died.

Case 7. 89 year old lady. Swallowing problems, long standing vague undiagnosed neurological problem. Doctors procrastinated—admitted too late for PEG. Died in hospital weighing six stones.

Case 8. Terminal cancer patient. Age 54. Sedated without hydration for eight days in hospice. Staff refused to set up a drip. Patient died in dehydrated state.

Case 9. Cancer patient in pain from isolated metastasis age 66. Not dying. Sedated without hydration in a hospice and morphine increased despite pain control. Died comatose and dehydrated after seven days. Widow finally after six years' struggle obtained an independent opinion that supported her view that the patient was killed to cure his pain. Legal aid withdrawn before case went to court.

Case 10. 85 year old woman in nursing home. GP covered. Could swallow liquid, tended to choke. CVA's and some dementia. Feeding supplements stopped by GP. Patient took 58 days to die of starvation and bronchopneumonia.

Case 11. Mrs W. Elderly woman in rural cottage hospital. Conscious, unable to speak, too weak to swallow. Found by locum doctor undiagnosed and dehydrated in a side ward. Responded well to subcutaneous fluids. Within days could speak and drink, happy to be alive. Considered to be a "ghastly survival" by in house team.

EXAMPLES OF MALIGN RELATIVES

In case 10 above, the relatives tired of waiting for Mrs O to die. Asked GP what would happen if feeding supplements were stopped. Collaborated in her death.

Case 12. Elderly woman in hospital not fit for discharge home. Money available for nursing care. One daughter hid this fact from doctors who sent her home against the wishes of another daughter. She fell within days and was readmitted with pneumonia and died. Scheming daughter got her inheritance.

Case 13. Terri Schiavo. Florida October 2003. 39 year old woman with cognitive disability after collapse from unknown causes 1990. Husband won 1.3 million dollars in a malpractice suit saying he would look after her for the rest of his life. Within months he got a DNR order placed on her and denied her medical treatment. He dated another woman and is now engaged to be married. In 1998 he petitioned a court to withhold tube feeding and fluids until she died claiming that this is what she wished on the basis of comments he states she made before she collapsed. Terri's patients dispute this. She responds to them and they are able to feed her orally. They want to look after their daughter but a judge refused and ordered her execution by removing her feeding tube and starving her to death.

21. Supplementary memorandum from Dr P J Howard (MIB 1204)

RESPONSES TO QUESTIONS 4 TO 8. DR P J HOWARD MA MD FRCP

4. *Do the provisions contained within the Draft Bill enable people to be sure that their beliefs with regard to treatment will be respected if they lose capacity?*

Advance Directives, as statements of the patient's wishes and background beliefs can be very useful in deciding a patient's treatment in the event of incapacity. However, it has long been held that positive statements regarding treatment made by patients in advance of their becoming incapacitated cannot bind a doctor to act against his/her clinical judgement. Nevertheless, there is no provision for indicative positive advance statements in the Bill. It is clear therefore that the Bill will effectively limit patient treatment options.

Patients will often make decisions regarding actual and specific treatment options over a period of time and may change their minds during the course of their deliberations. Patients will usually wish to consult friends and family and increasingly have recourse to the Internet for additional information. A doctor may be held negligent not only for failures in diagnosis and treatment but also with regards to the advice he gives to patients in obtaining valid and informed consent. The standards for obtaining valid consent in a contemporaneous setting are justifiably stringent. However far less stringent criteria would apply to advance refusals of treatment. In practice, advance statements will apply to the refusal of hypothetical treatment in the future rather than the acceptance of actual treatments in a contemporaneous setting. Patients will not usually have the opportunity to discuss treatment options with the doctor who will actually be responsible for patient care. This will mean that it will be difficult, if not impossible, for the responsible doctor to be sure of the patient's wishes. Moreover, there may be a considerable lapse of time between the refusal and its application during which there may have been advances in treatment about which the patient may be ignorant. Those of us who have dealt with Jehovah's Witnesses who have refused blood transfusion, with potentially dire consequences, will appreciate the anxieties that such refusals evoke in practice. The refusal of Jehovah's witnesses for blood products is well established and part of a well-recognised belief system. It is difficult to see how such a high level of certainty regarding an advance refusal could be made in any other context, particularly with regards to patients who are previously unknown to the doctor responsible for their care and where the patient's views and wishes cannot be known with the same degree of certainty. Advance Refusals ought not to be made legally binding on doctors.

5. *Should the Draft Bill specify that a person acting on behalf of a person with incapacity should have regard to their values as well as their wishes and feelings when deciding what is in their best interests?*

Medical decision-making is a two stage process. First, it requires an assessment of the patient's clinical needs and of the risks benefits and alternatives of treatment. Second, a decision by the patient as to whether or not to accept treatment. Notwithstanding the clinical assessment, competent patients are free both legally and ethically to refuse even worthwhile or necessary treatment. In other words, a patient may act against their own best clinical interests. However, the responsibility of the healthcare professional is to ensure that the diagnosis is accurate and the explanation of the proposed treatment options is sufficient for the patient to make an informed choice. When the patient is unable to make a decision because of incapacity, or the pressures of an emergency, the doctor must make a decision based largely on the clinical best interests of the patient with an emphasis on treatment of the underlying condition, relieving pain and suffering and preserving life. This is covered by the common law principal of necessity, which does not apply only to emergency treatment, but also to what is necessary even when of a rather mundane nature such as washing and dressing or routine dental treatment. A doctor may therefore act reasonably and ethically, if his treatment is clinically appropriate according to the principle of necessity and in accordance with the wishes of others involved in the patient's care such as friends, relatives and other carers. (Unfortunately, various studies have shown that proxies are often poor judges as to the would-be wishes of the patient. These have been mainly American studies in which patients and their proxies have been asked to indicate what treatment the patient would have chosen using a range of clinical scenarios and comparing the responses with those of the proxies). Reliance on the assessment of relatives and carers may also be misleading because of the understandable duress they may suffer especially with sudden or life threatening illness eg trauma, stroke or head injury. Hence, whilst taking into account the values as well as the wishes and feelings of patients is important in making decisions for the incapacitated, it is often difficult and unreliable in practice. Such considerations should not however, mitigate good medical decisions by doctors in emergencies particularly where the views of the patient cannot be ascertained with reasonable certainty.

6. *As in our society people choose to adhere to different values and beliefs, do you consider that the Draft Bill achieves the right balance between respect for individual diversity and respect for life? If not, what would you change?*

Unfortunately, following the Bland [1993] in the House of Lords and the Janet Johnson [1996] case in Scotland, life is no longer regarded as necessarily being of benefit to the patient. The concept of "respect for life" has therefore become rather broad. A more important principle is that no medical intervention should have as its purpose the termination of a patient's life by act or omission. Unfortunately, "respect for life"

may mean very different things to different people because of the plurality of beliefs within society. Quality of life judgements are often largely subjective and refer to assessments by healthy individuals on behalf of those who lack capacity. They are therefore both subjective and potentially misleading. Whilst doctors and other healthcare professionals have competence to decide the worthwhileness of a patient's treatment, they are not competent or qualified to decide the worthwhileness of a patient's life.

7. In your view does the Draft Bill distinguish between ending life by omission and not aiming to prolong life by inappropriate means? If not, what safeguards would you like to see?

The Bill would clearly allow the withdrawal or withholding of life sustaining treatment and care including the provision of hydration and nutrition. The withdrawal of hydration is a sure way of terminating life. Hydration and nutrition are not treatment of any condition, including stroke, PVS or MND but are the ordinary means of sustaining life for both the healthy and the sick. The Bill must not allow the withdrawal of hydration and nutrition with the intention of bringing about the death of a patient. Similarly ordinary treatment such as insulin should not be withdrawn with the same purpose. I agree with the statement made by Dr Wilks, on behalf of the BMA in answer to question 227:—

“Any doctor who makes a decision that someone's life in common parlance has no value and should be terminated and ends treatment with the intention of terminating life is acting illegally and unethically”.

8. Will giving advance refusals a statutory basis risk the welfare of patients? If so, how might the Draft Bill be amended to avoid this?

Advance refusals of treatment by “freezing” the wishes of a patient in the form of a binding legal instrument, will risk the welfare of patients and are open to misunderstandings and abuse. A suicide note would be a valid and applicable advance refusal that would prevent doctors from resuscitating patients after drug overdose. Advance statements, whether they are positive or negative statements, ought to be indicative and advisory rather than legally binding.

October 2003

22. Supplementary memorandum from the Lord Habgood (MIB 1206)

Q1. Would the inclusion of a legal definition of “best interests” clarify the legislative intent of the Draft Bill or would such a definition be unduly static and inflexible for decision-makers?

Insofar as “best interests” are a matter for clinical judgment, a legal definition would probably be unworkable. Clinical judgment may be usefully informed, however, by the concept of “medical necessity”, ie “treatment carried out to save life, or to ensure improvement or prevent deterioration in a patient's physical or mental well-being”. This is likely to be less subjective than “best interests”, and less closely linked with patient autonomy which, in the circumstances, is likely to be a difficult criterion to apply.

Q2. How should the individual's clinical best interests be balanced against their wider interests?

It depends on what “wider interests” you have in mind. Wishes, values etc are relevant. But while the administration of an individual's estate is clearly an “interest”, to balance it against the clinical judgment of “best interests” could lead to abuse. eg Should P be kept alive by artificial means in order to meet the seven year criterion for tax-free gifts?

Q3. In your view, should the General Authority be restricted to particular categories of medical interventions? If so, what restrictions would be appropriate?

Financial expenditure using P's resources should be subject to some external check.

Q4. Do the provisions contained within the Draft Bill enable people to be sure that their beliefs with regard to treatment will be respected if they lose capacity?

What beliefs are relevant? Would a belief in euthanasia count? hope not. Current rules about confidentiality can make it difficult for chaplains and other religious advisers to discover when issues concerning belief may be relevant to treatment or care. Ideally an appropriate religious or ethical representative should be part of the medical team responsible for making major decisions about P.

Q5. *Should the Draft Bill specify that a person acting on behalf of a person with incapacity should have regard to their values as well as their “wishes and feelings” when deciding what is in their best interests?*

Yes. But insofar as the question implies a proxy decision-maker, I would caution against this for reasons set out in the 1994 report.

Q6. *As in our society people choose to adhere to different values and beliefs, do you consider that the Draft Bill achieves the right balance between respect for individual diversity and respect for life? If not, what would you change?*

Diversity is to be respected, but the law necessarily sets limits because it depends on, and has to uphold, general social attitudes as well as individual liberties. Thus the fundamental reason why euthanasia is, and should remain, illegal is that to legalise it would in the long run generate a profound, and potentially harmful, change in social attitudes towards the sick, the incapacitated, and the elderly. Belief in euthanasia does not give the right to demand it. In the absence of any change in the law, it is important not to allow the present law to be circumvented. Clauses 23 (1 b) and 24 (5) could have this effect in cases where the lack of capacity is not thought to be permanent.

Q7. *In your view does the Draft Bill distinguish between ending life by omission and not aiming to prolong life by inappropriate means? If not, what safeguards would you like to see?*

There are serious and legitimate worries as to whether nutrition and hydration are ethically equivalent to the withdrawal of treatment. The Bland case set an unfortunate precedent. Since he was both incapacitated and completely unconscious the distinction was for him irrelevant. But it is not irrelevant for those who, though incapacitated, retain a degree of consciousness.

Q8. *Will giving advance refusals a statutory basis risk the welfare of patients? If so, how might the Draft Bill be amended to avoid this?*

There are inherent problems in specifying in precisely in advance what conditions and circumstances should be sufficient to bring a refusal of treatment into effect. This is one reason why the name Advance Directive is to be preferred to Advance Decision. A decision is the end of a process, whereas a directive can be an important element within it. To assume that a decision can be made, and must be adhered to, before the precise circumstances can be known, must be to put the welfare of patients at risk. A directive, on the other hand, should be seen as giving valuable guidance for the exercise of proper clinical judgment, as well as protecting doctors against charges of negligence.

Q9. *Should the Draft Bill stipulate that advance decisions must be made in writing?*

Yes.

Q10. *In your view are the safeguards in the Draft Bill sufficient to protect individuals who suffer from fluctuating levels of capacity?*

No. There needs to be a reasonably firm prognosis before any decision is made—and this may take time (at least a year in the case of PVS). This is a further reason why clinical judgment is to be preferred over the legal implementation of advance decisions.

Q11. *The Draft Bill puts into statute the current common law position as regards advance refusals. Would denying capable individuals the right to make statutorily enforceable advance decisions to refuse treatment amount to a form of discrimination against people who later become incapacitated?*

No. A degree of flexibility is necessary for the protection of patients, given that medicine is not an exact science.

Q12. *Do you envisage that there are any medical circumstances when the wishes expressed in a valid advance directive (or a person's wishes expressed through a donee acting under an LPA) might reasonably not be followed by the treating doctor? If so, can you give examples?*

When there is real uncertainty about the prognosis, eg Is it PVS or coma? What degree of recovery from a serious stroke is likely? How quickly will Alzheimer's advance? What are the chances of new treatments being available in time to make a difference?

Q13. Should the Draft Bill exclude "basic care" or a "minimal level of care" from its procedures and mechanisms? If so, how should "basic care" or a "minimal level of care" be defined?

Basic care is owed to everyone, whether or not they want to die. This must include paying respect to P's body by keeping it clean, as comfortable as possible, and not subjecting it to unnecessary indignities. On nutrition and hydration, see 7. Some particularly invasive forms might be classed as "treatment" and, to that extent, not part of basic care. There is a case for not including antibiotics as a regular part of basic care. My own view is that this is what should have been done in the Bland case.

Q14. Do all the witnesses agree with the Catholic Bishops' Conference view that the Draft Bill currently contains insufficient safeguards against donees who fail to carry out their responsibilities properly? If so, how should these safeguards be increased?

Clause 22 seems to deal satisfactorily with this point.

Q15. Should Local Authorities be given duties to investigate possible abuse taking place under the provisions of the Bill? Would this approach help to address any concerns you might have about the exploitation of vulnerable people?

Presumably those with major long-term mental incapacity are already known to Health Visitors and Social Services. If not, surely they should be.

October 2003

Tuesday 14 October 2003

Members present:

Barker, B.	Mrs Angela Browning
Carter, L. (Chairman)	Mr Paul Burstow
Fookes, B.	Stephen Hesford
Knight of Collingtree, B.	Mrs Joan Humble
McIntosh of Hudnall, B.	Huw Irranca-Davies
Pearson of Rannoch, L.	
Rix, L.	
Wilkins, B.	

23. Memorandum from the Association of Directors of Social Services (MIB 1040)

INTRODUCTION

1. The Association of Directors of Social Services (ADSS) is a network of Directors in England and Wales. It conducts most of its business through a series of Committees, including Disabilities, Older People and Resources.

2. Local Authorities with Social Services Responsibilities have a direct interest in the content of the draft Bill and its implementation. They have substantial involvement with a large number of people with mental incapacity, including older people, people with learning disabilities, and people with mental health problems. The involvement of Social Services Departments includes the following:

- (i) Assessment and Care Management of people with community care needs.
- (ii) Functions under the Mental Health Act (1983) including: assessments for compulsory detention or guardianship; and circumstances when the Director of Social Services is appointed as a Receiver by the Court of Protection.
- (iii) Local agency lead in multi agency adult protection arrangements.
- (iv) Provision of community care services and residential care.
- (v) Commissioning community care and residential care from the voluntary and independent sector.

3. The commissioning and delivery of services for people with mental incapacity is increasingly undertaken in partnership with the NHS, including arrangements under Section 31 Health Act. In particular, the majority of adult mental health services in secondary care are now delivered through integrated management arrangements with mental health trusts.

THE BILL

4. The ADSS has previously commented in brief on the proposals (Annex 1). The ADSS broadly welcomes the proposals contained within the draft Bill as a significant and long overdue step forward in providing a legal framework for people with mental incapacity. The Bill has significant implications for service delivery and there will be costs associated with implementation. These need to be reflected in the Formula Spending Share settlement between Local Authorities and Government. The ADSS would like to ensure an ongoing dialogue with the Department for Constitutional Affairs and the Department of Health throughout the development of the Bill and the Codes of Practice. The following comments address particular aspects of the draft Bill.

Annex 2 includes a draft submission to the Department for Constitutional Affairs on the impact of the Bill on Local Authorities.

5. Part 1: *Persons who lack capacity*

Clauses 1–5: *Preliminary*

Clause 3: The presumption against lack of capacity is crucial. We are concerned about the risks to individual liberty, and to the possible increasing demands for public services to intervene in lives of people, and would welcome a strengthening of the wording of this section in the Bill, and in the Code of Practice.

Clause 4: *Best Interests*

The Code of Practice should give guidance on the matters that need to be taken into account, noting the guidance and case law in “Making Decisions: A Guide for Social Care Professionals”.

- Clause 5: We note the extension of powers from those under the current Mental Health Act and the need to consider the impact on childcare and child protection practice.
- Clause 6: *The General Authority*: this clause needs additional guidance in the Code of Practice as follows:
- (i) for people, including care staff who act under this authority;
 - (ii) the relationship with duties under the Care Standards Act;
 - (iii) the relationship with Appointeeship procedures and the management of benefits.
- Clause 7: The Code of Practice should address the relationship with proposals for Compulsory Community Treatment under the Mental Health Bill, which we presume will replace the current provisions for Guardianship under the Mental Health Act 1983.
- Clauses 8–13: *Lasting Powers of Attorney*
Our main concern under these clauses is the scope of Social Services responsibilities when it is suspected that donees of LPAs are abusing their authority. Social Services have established Adult Protection arrangements under the Department of Health's "No Secrets" Guidance, and these could provide a local framework under which these matters are considered.
- (i) the role of Adult Protection arrangements should be addressed in the Code of Practice;
 - (ii) Clause 10: as with Clause 7 this requires guidance in the Code of Practice regarding the use of Compulsory Community Treatment powers (currently Guardianship) in the Mental Health Bill.
- Clauses 11–20: *General Powers of the Court and the appointment of deputies*
- Clause 15: We note the inclusion of an adult protection dimension: "*the lawfulness of an act, omission or course of conduct in relation to that person*" which is an addition to current requirements under the Mental Health Act.
- Clause 16: *Powers to make decisions and appoint deputies: general*
This clause has significant implications for Directors of Social Services. The current arrangements under the Mental Health Act allow for Directors to be appointed as Receivers to manage the financial affairs of people with mental incapacity. There is widespread variation in the use of this power by Social Services Departments. The new proposals extend the powers to welfare decisions. The implications include the following:
- (i) Directors will need to review their local policy and practice on the use of discretionary powers under incapacity legislation;
 - (ii) the extension of the powers to welfare decisions is likely to result in additional demands on services which are already at capacity;
 - (iii) the extension of powers could require Directors and Social Services staff (and Elected Members) to engage in decisions of an ethical nature that they have not previously been required to take;
 - (iv) additional demands on information systems; and
 - (v) the performance or other reporting and review arrangements that may be placed on Local Authorities.
- Clause 17: As with Clause 7 the Code of Practice should identify when powers under the Mental Health Act would be more appropriate.
- Clause 19(7): Local Authorities must be entitled to charge on an equivalent basis to other bodies for carrying out duties under the Act. A fair and consistent charging mechanism is likely to be achieved only if determined by the Court. Local Authorities would expect to be able to charge for all costs associated with undertaking duties under the Act including administration costs and additional care management (social work input).
- Clauses 23–25: *Advance decisions*
This is a welcome inclusion in the Bill. Effective implementation of this section will require a public information strategy, including the need for a structured approach to life planning, the making of wills, etc; and the role of the private and voluntary sectors in these matters.
The Act or Code of Practice should define treatment, including whether this is the same definition as in the Mental Health Act Code of Practice.
The implications of these proposals for Social Services:
- (i) advance decision should be considered as part of an assessment of community care needs (some Mental health Trusts now include Advance Directive documentation in their Care Programme Approach assessment, but this is not yet common practice);

- (ii) there are considerable training implications for care staff. The arising practice issues need to be included in the new Social Work degree; and in the range of training for non-professionally affiliated staff. It should be noted that the majority of care staff will not have a professional qualification;
- (iii) some experience from USA suggests that the preparation of Advance Directives raises ethical and spiritual/religious issues for a person and those involved in their care, eg refusing life sustaining treatment, and for which people are ill prepared to consider. Competency to practice in this area requires a degree of "ethical and spiritual literacy".

Clauses 26–29: Excluded decisions: no comment.

Miscellaneous and Supplementary

Clause 30: *Code or Codes of Practice*

This response to consultation includes reference to matters that should be contained within Codes of Practice.

The ADSS would expect to be consulted during the preparation and revision of a code of practice; and likewise all Local Authorities and NHS bodies. Effective communication with these bodies can be achieved through the weekly Chief Executives Bulletin issued electronically by the Department of Health, and with Local Authorities through the ADSS Bulletin.

Clause 31: *Ill Treatment and Neglect*

The Code of Practice or other guidance should clarify the liability of the Director of Social Services as a deputy if an employee commits an offence under this clause.

6. *Part 2: The Court of Protection and the Public Guardian*

Clause 34: The Court of Protection. The inclusion of provision of more local and accessible Courts is welcome.

Clause 39: *Power to call for reports*

The new power for the Court to require a local authority to arrange for a report to be made is noted. We request further information on why this power is required, the anticipated demand, and the criteria for using the power. We also seek an assurance that Local Authority staff will not be used as a substitute or replacement service for Lord Chancellor's visitors.

Clause 41: *Court of Protection Rules*

The implementation of the provisions in the Bill would be facilitated by the publication of a publicly accessible version of the Rules to assist the public and professionals in the preparation of applications.

Clause 45: *Costs*

Local Authorities would expect to be awarded costs for expenses incurred in the course of proceedings in the Court of Protection. Legal aid should be available to parties in proceedings.

Clause 47–49: The Public Guardian and Lord Chancellor visitors: no comment.

7. *Part 3: General* No comment.

8. *Matters not covered in the Bill:* We note the comment in the Explanatory Notes that the Hague Convention of the International Protection of Adults 2000 and request consultation on the provisions to be inserted into the Bill prior to its introduction to Parliament.

August 2003

Annex 1

Draft Mental Incapacity Bill Consultation

I was disappointed and somewhat alarmed to hear today that the consultation on the draft Bill closes on 1 September, a date that has not previously been communicated to me or my colleague Directors of Social Services. The proposals contained within the draft Bill have significant implications for Councils with Social Services Responsibilities, and both individual authorities and the ADSS collectively require sufficient time and notice to prepare a useful response. When the draft Bill was published on 27 June the accompanying letter from Chris Walker said quite clearly "Once it is established the (Joint) Committee will let people know the timescale to which it is working". This has not happened. I would however like to make the following comments:

1. The ADSS broadly welcomes the proposals contained within the draft Bill as a significant and long overdue step forward in providing a legal framework for people with mental incapacity.

2. The assumption against lack of capacity is a crucial principle, and if possible this should be strengthened in the Bill and in the Code of Practice.

3. The Bill contains a number of proposals that require more detailed examination eg the implications for Authorities concerning advance statements; and the implications for Directors and Elected Members of welfare matters included in the scope of Lasting Powers of Attorneys. In addition, Councils with Social Services Responsibilities (CSSRs) have the lead for adult protection, and have established partnership arrangements that could provide a useful local framework to address the protection issues arising from the legislation.

4. The ADSS expects CSSRs to be actively involved in the development of the Code of Practice. There is a substantial level of expertise within Social Services Departments that would add value to the quality of the Code.

5. The timescale for consultation that was imposed subsequent to publication of the draft Bill was too short and inadequately communicated to major stakeholders. The ADSS notes that consultation events have been planned by the Department into the Autumn and expects that the formal response from the ADSS will be accepted beyond 14 October, the last consultation event that we have been notified of.

6. The Partial Regulatory Impact Assessment acknowledges both that the Department of Constitutional Affairs "is seeking to reduce centrally issued guidance and devolve more responsibilities to the NHS/ Councils with Social Services Responsibilities"; and that the costs of complying with the legislation will be borne by a number of stakeholders including CSSRs. CSSRs must be fully consulted, and with reasonable timescales, in the forthcoming impact assessment.

7. Further consultation on the draft Bill must be more effectively communicated with stakeholders. The launch of the draft Bill was communicated through the Department of Health's Chief Executive's Bulletin, and this is an effective vehicle for communication with the NHS and CSSRs. In addition, information should be sent to the ADSS, with me as the contact point.

I would be grateful if you would acknowledge receipt of this letter and give me your response to the points raised, in particular a commitment for effective consultation and communication about work in progress concerning the draft Bill.

John Dixon

ADSS Chair of Disabilities Committee

Annex 2

Draft

ASSOCIATION OF DIRECTORS OF SOCIAL SERVICES

The Draft Mental Incapacity Bill: Impact Assessment

This document supplements the Association of Directors of Social Services (ADSS) formal response to the draft Mental Incapacity Bill.

1. THE CODE OF PRACTICE

Proposals for issues to be covered include:

- Clause 3: Presumption against lack of capacity.
- Clause 5: The impact on child care practice and relation with other statutory guidance and processes.
- Clause 8–13: *Lasting Powers of Attorneys*
 - (i) links with multi-agency adult protection arrangements;
 - (ii) the link with powers under the Mental Health Bill/Mental Health Act;
 - (iii) Deputies and their responsibilities in relation to legislation covering confidentiality and access to information.
- Clause 23–25: *Advance Decisions*
 - (i) advance decisions as part of the consideration in an assessment under the Community Care Act and Mental Health Act;
 - (ii) there is considerable other guidance required, some already available that should be incorporated in the Code.
- Clause 39: *Power to call for reports*
 - (i) the criteria used to decide when Lord Chancellor's Visitors and Local Authorities are to be asked to provide a report;
 - (ii) guidelines and a template for reports.

- Clause 41: *Court of Protection Rules*
An accessible version of the rule would provide assistance in preparing applications for the Court.
- Clause 45: *Costs*
Reference to guidance published by the Court on what costs can be recovered for assisting in proceedings.

2. GUIDANCE

The ADSS would support the production of central guidance and would encourage Social Service Departments to share local guidance where this is available.

3. IMPACT OF THE BILL

Practice Issues

3.1 The Bill has wide implications. Some authorities estimate that 50 per cent of older people receiving social care services have some degree of cognitive impairment, in addition to adults with mental health problems and people with learning disabilities in receipt of social care.

3.2 The introduction of the Bill could require a review of current assessment and care management practice, including risk assessment. These are concerns that the Bill could result in additional demands on Social Services from the public, relatives and friends, and other care professionals, to intervene in people's lives when there are signs of mental incapacity. There are particular pressures when an individual is in a hospital bed. Issues of delayed discharge, reimbursement and risk-averse practice could compromise an individual's choice. In order to promote the independence of the individual within a framework of acceptable risk it is essential to base care decisions on a sound assessment of need and risk. Failure to do this will limit independence and could result in unnecessary use of residential care resources. The Code of Practice will be crucial to assisting individual's professionals and carers in these decisions.

3.3 Some authorities have suggested that whilst risk assessment and management practice in adult mental health services is well developed this is not so in other services. It is worth considering the case for the development of tools to assess and manage risk including that arising from mental incapacity, that are more widely applicable.

3.4 The best interests of an individual will be promoted by easy access to independent information, advice and advocacy. We would like to know what proposals are being developed to enhance access to these services through the voluntary and independent sector, including the resources made available.

Local Authorities do not have the duty, or the resources, to secure the provision of support and advocacy, which is usually best provided by independent bodies.

Training and continuing professional development

3.5 Many of the paid carers working with people with mental incapacity will not be professionally qualified. Significant additional training resources will need to be deployed to ensure that staff operate within the framework of the Bill and Code of Practice. This will include staff employment directly by local authorities, and those employed in voluntary and independent sectors who provide services under care contracts with local authorities.

3.6 The requirements of the Bill will clearly need to form part of professional training. Social Services Departments will also clearly need to ensure the existing workforce have adequate training, development, and access to guidance and advice. Some authorities may choose to develop local mental incapacity practice guidance, based on the Code of Practice and national guidance. Given the multi-disciplinary nature of care, it would be desirable for much training to be developed on a multi-agency basis with NHS, voluntary and independent sector staff. Existing multi-agency training in adult protection will also need to be revised.

Finance

3.7 The Bill is expected to result in increased costs to Local Authorities arising from additional demand for assessment and interventions under the welfare provisions for Court Deputies, and the provision of Court reports. There will also be additional costs from training, and central support costs including legal advice and preparation of papers for the Court.

3.8 The Bill makes provision from the recovery of costs in legal proceeding, and other duties carried out for the person with incapacity. Local Authorities will expect to establish charging policies and procedures to recover costs for some services provided.

3.9 There may be other financial implications that are advantageous to Local Authorities.

- (i) Local Authorities occasionally incur debt from individuals with mental incapacity that has to be written off. Early intervention and the establishment of robust financial arrangements could ensure the appropriate collection of charges for care.
- (ii) A proactive response with local solicitors and voluntary sector advice and advocacy agencies to the Bill could promote the development of life planning, including the making of wills, Lasting Powers of Attorney, and advance decisions. This would assist Local Authorities in determining an individual's best interests, and minimise the need for Local Authority intervention.

Information

3.10 Local Authorities will need to provide staff and service users with a range of information. This is covered elsewhere in this report. Electronic information systems will need to be reviewed to ensure that activity in connection with the Bill is captured and can be aggregated for performance management purposes.

3.11 The Bill and explanatory notes make no reference to the roles and responsibilities of Deputies in relation to consent and access to information on confidential records. Local Authorities will need to be advised of their powers and duties in managing the information of people who are unable to consent to disclosure; and of its responsibilities when the Director of Social Services is a deputy.

John Dixon

Director of Social Services West Sussex
Chair, ADSS Disabilities Committee

Witnesses: **Mr John Dixon**, Chairman, National Disability Committee, **Mr Graham Collingridge**, Member, Mental Health Strategy Group, Association of Directors of Social Services, examined.

Q426 Chairman: Thank you for your written evidence, which is very helpful, and for coming today. As you know, the session is open to the public and it is being recorded for broadcasting. In fact, we should be on the Parliament Channel at six o'clock on Sunday evening, if you are interested. There will be a verbatim transcript of the evidence which will be published with the report, and you will be asked to check the text of the transcript for accuracy. If there is a division in either House then we shall adjourn, and there should be a note on the table of the relevant interests of Members in this Bill. As I have said to all the witnesses, if we are unable to reach all the questions and if you would like to respond in writing, or, indeed, on any of the points that arise in discussion, please write to us. We are required to report on the draft Bill. We are not asked to report on a White Paper on mental incapacity, so that is why all the questions are structured around the Bill. If you would like to introduce yourselves?

Mr Dixon: I am John Dixon. I am Director of Social Services in West Sussex and I am Chair of the Disability Committee of the Directors of Social Services, the national association.

Mr Collingridge: My name is Graham Collingridge, I am County Manager for Mental Health with Hampshire County Council, and I am on the ADSS Mental Health Strategy Group.

Q427 Chairman: As you know, there is already a framework of case law which governs the area of mental incapacity. How does this Bill make things better? Also, has the consultation between the department and the Directors of Social Services been adequate? Are you confident that further consultation over the Codes of Practice, which will be very important, will be adequate? The final part of this question is, do you feel there is enough in the Bill or is too much being left to the Codes of Practice?

Mr Dixon: I think the first thing that I would like to say is that I think a lot is being left to the Code of Practice at the moment. We feel that there has been the beginnings of consultation between the department and stakeholders, including ourselves, and we have appreciated that this is a novel approach to the construction of this Bill and we have been keen to respond to that. However, on the whole we think that we are not yet speaking in the same language, so that communications to us have not been direct and there has not been the use that there should have been of the Department of Health channels for talking to chief executives and others. We have made those points and we hope that that is going to be rectified in terms of the type of communication. We have had, I think, a good meeting of minds in the discussions we have had. On the larger point, I think that there are aspects which could have been brought out significantly further in this Bill than were. Those are things that from the social services' point of view we would particularly be able to comment on, and we have spoken—I have spoken personally—with our service users who have very strong views about this. So although I think the Bill is beginning to move in the right direction there are other opportunities that could be taken to take things further because it needs to complement national policy in this area, particularly around issues like valuing people—people with learning disabilities. It is important to hear from service user groups about what the implications of the Bill will be for them, because there are many people who would say, and we would endorse that, that it could be seen as a charter for carers or a charter for social workers rather than a charter for service users. Does it adequately consider the needs of service users? Does it signify the sort of major shift that I think has been seen in public policy over the last few years, both under this Government and the last one, about the expectation of what social services should be able to

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deliver for service users in the same way as the Children's Act signified a fundamental shift of approach and is still regarded as at the cutting edge of public policy 14 years on? My feeling is that this Bill goes a distance but in another five years' time could well be seen as outdated because it does not take forward adequately the notion of citizenship of people who are vulnerable. For example, we say there is no mention of the word "advocacy" in it. Without advocacy people cannot adequately speak for themselves. We, the social workers, would not presume to speak for people who have mental impairments and we think that lawyers and others should not do either. So we think it is a step but it needs to go significantly further if it is really going to enhance the citizenship of these people.

Q428 Chairman: Surely we are not going to wait another five years if these things are understood now? Would you recommend that we should put them into the Bill?

Mr Dixon: Yes.

Q429 Chairman: How would that be done? By extra clauses? What is a specific example?

Mr Dixon: I think it is about a shift more towards enabling people to be able to speak for themselves. There are certain presumptions against people being able to speak for themselves or with people who will be advocates for them.

Q430 Mrs Browning: Can I ask you how you are seeing the role of the advocate in this respect? Is it somebody who is independent, not a named social worker but somebody quite stand-apart who is answerable to the department that has the resources? That is a dilemma for advocates who are also the named social worker.

Mr Dixon: It is absolutely essential. In this context I would not describe certainly a social worker nor even indeed a legally qualified person as an advocate; we are talking about somebody who is completely outside of anybody who has control over resources. That is absolutely paramount. It is very likely they will be from a voluntary organisation. That is the normal way in which we work.

Q431 Mrs Humble: There is a later question about resources for advocacy and I do not want to trespass upon that area, but there are two issues here. One: should there be a national advocacy service just to complement the clauses and the elements in this Bill where advocacy may be of some use? Or are you looking at enhancing the development of local advocacy services—and they are patchy? I declared an interest as regards the Blackpool advocacy, and I know the excellent work that Blackpool advocacy services does do. Many of the local advocacy services have time-limited funding to undertake specific projects. Hopefully, if this draft Bill becomes legislation, it will go on rather more than five years and for some time. Are you envisaging a national service that people can fall upon to make sure that

this Bill is properly implemented, or would you still be relying on the local services and that patchy network of local services?

Mr Dixon: I would be expecting to see national standards and national expectation that advocacy is available which requires funding. At the moment, we do fund—social services departments and others—a significant element of advocacy. I would not necessarily go so far as to say there should be a national advocacy service because that could be a pretty unwieldy beast and may not actually have the sensitivity to local circumstances that we would like to see. I would expect that there would be an expectation that service users should have access to advocacy. It should be a right, particularly in these circumstances.

Q432 Mrs Humble: You were talking earlier about your concerns on behalf of the ADSS. One of the issues with regard to this Bill is that there has been a lot of concentration on the medical elements of it and the role of clinicians and what happens when an individual lacking mental capacity goes into a hospital. Of course, many of the people with whom this Bill is concerned will, as you have said, be capable of communicating. What more, if anything, can be done to emphasise that point, and the fact that the legislation is actually looking at that much wider group who are in the community cared for either on an informal basis or through statutory agencies like social services?

Mr Collingridge: One of the things we are wondering about is—right up the front of the Bill—emphasising that people with mental incapacity or possible incapacity are citizens, and have that right up front, along with duties to promote citizenship. We know there is a lot of concern from, for example, people with learning disabilities that they will lose the rights that they have currently just won through Department of Health policies like valuing people and the national service frameworks for people with mental health problems. I think perhaps right at the very front of the Bill, to make that first point very, very clear, and also in the Codes of Practice, that we are promoting individual civil liberties. We were very heartened this morning to hear Lord Filkin talk about the new role of the Department for Constitutional Affairs and how that is what he wants to see, promotion of rights and civil liberties in the 21st Century, and not just making the current system work better. There should be more of a shift in the Bill on that emphasis.

Q433 Chairman: If the Bill states there is a presumption of capacity unless proved otherwise, that is the same as every other citizen. Is that not enough?

Mr Dixon: I have worked in social services for a long time now and we have seen a sea-change in the way we need to relate to people with vulnerabilities. It is not just enough to say that they are citizens like anybody else and therefore they need, as it were, to exercise their rights like anybody else. People need assistance in order to explain what they want to see happen and assistance in realising those life choices.

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We need to make a very active reaching-out in order to enable people to do that. It is a qualitatively different approach and it is remarkable what people can do if we do reach out to them in that way.

Q434 Lord Rix: You are saying you would like to see provision for advocacy at the beginning of the Bill. Is that what you are saying?

Mr Dixon: Yes.

Q435 Lord Rix: If so, how are you going to provide the additional resources necessary to provide this advocacy?

Mr Dixon: The question of resources is something that we are going to need to come to. It is not mentioned; it is regarded effectively as being cost-neutral, I think, in the way this Bill has come forward. We feel very strongly that it does need to be resourced. If it is going to produce qualitative outcomes, different outcomes, for people then it is going to require a different level of resourcing. One of the key areas is not within social services but, as I say, within the resourcing the voluntary organisations will need in order to help people with incapacities to become fuller citizens.

Q436 Lord Rix: Do you mean it would be similar to Section 64?

Mr Dixon: Indeed.

Q437 Baroness Fookes: You have stressed the importance of advocacy services. Could you have a stab at the kind of clause that should be added to the Bill, if not now later on?

Mr Dixon: Certainly, yes. I would not want to venture to do that at this stage, unless Graham has—

Mr Collingridge: I am not going to now, but we would be delighted to assist you.

Q438 Baroness McIntosh of Hudnall: Going back to your earlier remarks, you said you thought the Bill, as it stands (and I do not think I am misquoting you) “could be seen as a charter for carers or service providers rather than service users”.

Mr Dixon: Indeed.

Q439 Baroness McIntosh of Hudnall: You are implying in that that the presumption in favour of capacity is not, amongst other things, strongly enough worded. Can you give us any indication of how the wording could be better constructed to strengthen the idea? If we do not do that with the Bill, what dangers do you think those who are intended to benefit from it will be in as a result?

Mr Dixon: Shall I take the second one first? Can I say the good thing is that it confers upon carers and social workers the ability to act in ways that previously might have been seen to be illegal. This is seeking to remedy that and it is important that that should be addressed, because otherwise people will feel vulnerable when they are acting in people’s best interests. That is at the heart of the Bill. The problem is that it could, in the wrong hands, be tipped in another direction. You or I, if we were walking down the road and we looked a bit weird or we were

behaving a bit weirdly, could be set upon by somebody with a general authority and taken in hand, or, more likely, one of our children. That is an extreme case, but it potentially is open to that degree of abuse. Vulnerable people, people with learning difficulties and others, are quite open to being coerced by people around them. That is what we are concerned about.

Q440 Baroness McIntosh of Hudnall: How would we write on to the face of the Bill the kind of language that would prevent that from being possible?

Mr Collingridge: We have had some thought about this since we saw this question and we are wondering whether or not it is not the right question.

Q441 Baroness McIntosh of Hudnall: You think of the question and I will ask it!

Mr Collingridge: We do not think it is simply a question of tweaking a few words in a clause. Going back to the earlier point about citizenship and advocacy, if that is there then I think people will have more confidence that their needs and rights are being met.

Baroness McIntosh of Hudnall: Maybe.

Q442 Lord Pearson of Rannoch: My Lord Chairman, I am not quite sure whether my question should come under the first question or this one, but I wonder if I could put a question, speaking as a parent on behalf of the families of the severely learning disabled, or people with a mental handicap or intellectual disability—however you choose to describe it? I notice in your submission, MIB1040, under paragraph 2 showing the five areas of involvement which you see social services departments having, you do not actually mention liaising with families. As I expect you are aware, thousands of families of mentally handicapped people do feel they get bogged down and are not particularly well-helped by social services. We have indeed, if I can just quote it very briefly, a supplementary memorandum from one of our Scottish witnesses, looking at the experience so far of the Scottish Bill. She says: “Unfortunately, some of the practices of certain local authorities have been viewed as bullying tactics by relatives and carers, where situations of resistance arise, particularly as regards where an adult should reside.” She goes on to say “The particular problem is when the family feels that the adult should continue to reside in a care home setting but the local authorities insist that the adult moves out to live in the community”, and she gives various examples. Do you accept that there has been a problem in this area? How do you see the families of these people being helped; perhaps their wishes being balanced in future with those of the professionals in general? Or do you, when you refer to service users and citizenship and advocacy, really feel that a lot of these families are not very helpful and that their views are not quite, perhaps, as accurate and professional as your own?

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Mr Dixon: No. Firstly, I should say that usually it is the parent who knows more about the child and the needs of the child than any professional.

Q443 Lord Pearson of Rannoch: I agree.

Mr Dixon: It is the way in which parents have fought for the needs of disabled children which has begun to force the sea-change in public attitudes that I was referring to earlier. In the time that I have worked within social services I think we have come to the era of professionals being much more humble than we were in the past, because we do not have any monopoly on knowing what is right. I think the valuing people proposals are very, very helpful in that way, and I think we are constructing a new way of hearing what people say and responding to it. That is, of course, service users but it is also families, particularly when you are talking about disabled children who could, of course, often be adults.

Q444 Lord Pearson of Rannoch: I am grateful for that. Of course, a lot of the parents who are looking after many of these people are now starting to die at a greater rate. You would be quite happy to see parents and families becoming deputies, providing that there were not obviously after Aunt Agatha's money?

Mr Dixon: Yes, we would.

Q445 Stephen Hesford: Can I bring you back to what you were speaking about before because, speaking for myself, I am quite confused by it? This Bill has a functional approach and we have heard evidence that that is in fact a struggle. What you seemed to be saying before was not a functional approach, and it seems to do with the issue of human rights. If this Bill was human rights compliant (a) would that not deal in part with what you were speaking of before? The Scottish legislation, which we have heard quite a bit about, does not deal with advocacy on the face of the Bill, and we have heard that that functions satisfactorily, certainly as far as the Scottish system is concerned. It does not mention citizenship at all either, but it has a series of principles. What is the difference between what you were saying before, what we have got in front of us and what the Scottish Bill does and how can you firm it up—in terms of a clause or something that we can get a grip of—in terms of speaking about advocacy and citizenship? I just could not get a grip of what you were in fact saying to us.

Mr Dixon: I think it is a question of whether you see yours as being able to capture the sort of shifts in public policy and ethics, rather than simply being functional. I saw the way that the Children Act described a new definition, as it were a contract between the state and families and children, as representing a significant difference. I do not think this Bill begins to approach that yet, and that is what I am sorry for. I am not a legal draftsman, so I could not comment precisely on how it should be put into effect, but I think that it should be able to capture the changes in public policy that have taken place in

recent years and to, as it were, hand them across to local authorities and others to begin to take them forward in practice.

Q446 Chairman: If we did decide to include the principles of the Bill at the beginning, which has been suggested of course, that would help to meet your point?

Mr Dixon: It would indeed.

Q447 Mrs Browning: Can I explore this a little further because I am rather in sympathy with the case you are making. At the moment, and I include myself in this, for those of us who are involved very much with adults with learning disabilities and the sort of problems they come up against, one of the biggest problems is that there appears to be no real statutory framework against which one challenges. Ultimately, in case work, much as one loathes to do it, one gets to a point where the advice is to test it in a court. I am sure you will agree it is becoming far more frequent now to challenge social service departments in the courts on behalf of adults with learning disabilities.

Mr Dixon: Yes, indeed.

Q448 Mrs Browning: Do you see what you are proposing helping to minimise that recourse to problem resolution? I am hesitant because the resource implications of it are enormous. However, at the moment the resource implications are enormous because you are having to call expert witnesses across the legal process, etc etc. Do you see that helping to minimise the challenges through the courts?

Mr Dixon: Yes, I do. I think there is a place for law in providing that framework and in prodding local government to move in that direction. The resources that are spent in this area in relation to the legal challenge, at the moment, are significant but not overwhelming. It is, really, the resources which are spent on poor quality treatment and services for people with learning difficulties that are the real crying shame.

Q449 Mrs Browning: I agree with you.

Mr Dixon: Having somebody in a very expensive place inappropriately is bad for everybody and bad for the public purse. Obviously, I speak from a very pragmatic point of view rather than specifically from a legal point of view, but I do know the help there can be in having a good framework.

Q450 Mrs Humble: I am not quite as phlegmatic as either you or Angela Browning that this Bill will actually help you. Anyway it goes back to Lord Pearson's point about the role that parents have to play in this. I tell you why I have one or two concerns, for two reasons. One, traditionally social services has been in the risk business. Social services push people as far as they can go, and for the group of people that this Bill is concerning—either those who totally lack capacity or, more importantly, those who have variable capacity—the social worker temptation is always, always to push them as far as

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they can go in making decisions on managing their own lives. Yet parents get desperately worried about that. Many of the disagreements between social services and parents are because the parents want to cocoon that child as it becomes an adult and well into adulthood and want them protected—want them in the care home or nursing home—and social services say “Actually, your adult offspring can, with support, be in the community and should be engaging with the community”. So there is always that tension. Specifically, this Bill makes reference to the fact that the person with a variable capacity, especially, or even somebody who has capacity and then is likely to lose it, may make decisions that you or I disagree with. We have to accept that those decisions are ones that we do not agree with. So will that not add to some of the very difficult decision-making processes that social workers have to go through? They already have an extraordinarily difficult job to do but when they are having to deal with parents who, by and large—and I am generalising—are very protective, and are having to deal with people where they have to, because of this Bill, acknowledge that neither the social worker nor the parent may agree with those decisions, will this not, in fact, make your job even more difficult? Tell me it will not.

Mr Dixon: I think people have a right to make decisions which are independent of professionals and independent of their parents. That is important, and we need to ensure that they can do that. On the other hand, I think one of the reasons that parents have difficulties with social service departments and why they are anxious about protecting their children is because they very often have little or no guarantee that they are going to get services. If you have fought for services for your child for 20 years against an unforgiving system which has only allowed you services inch by inch, I think you get desperate. As you get older you are worried about what is going to happen when you are too frail to look after your child. I think it creates a feeling of protection as opposed to risk-taking. I would not want to criticise colleagues, but when saying that you can take a risk with this child it is the parents who are going to be around if it falls down; the social worker may have moved on or whatever. I think it is much more about creating a partnership between us, as social service departments and parents, in a mature way. I think if we have a framework which enables us to do that it will make our job easier, because we cannot be adversarial.

Q451 Huw Irranca-Davies: Can I ask you to help me summarise the preceding discussion? In terms of the Bill as a whole, as it is currently presented, and the rights of the individual—the user of these services—what we have in the Bill is an improvement but it is not bold and ambitious.

Mr Dixon: Indeed so.

Q452 Huw Irranca-Davies: The Scottish Bill, from what you were suggesting, would be an improvement even further in terms of this

clarification of the rights of individuals. What you are putting to us is that you would like us to have a step-change, in effect.

Mr Dixon: Indeed.

Q453 Huw Irranca-Davies: Which would be way above what the Scottish Bill has and certainly what this has at the moment.

Mr Dixon: That is indeed it. I think the problem is that in the public policy of this country we are moving fast on child care policy and it is very exciting. In relation to older people there is great ferment about what should happen and so forth. However, in relation to people with disabilities it is in the “too difficult” box. There is a tremendous amount of change in there, I think, waiting to get out. Talking to service users and their parents, I think there is a great opportunity to move things forward. It would encapsulate quite a lot of what is beginning to be around in government policy, which is very helpful.

Q454 Baroness Knight of Collingtree: I do want to come back to the question of resources. I notice that when you were writing on Clause 16, your second point on that clause was “the extension of the powers to welfare decisions is likely to result in additional demands on services which are already at capacity.” Now some of us, particularly those who read in the newspapers of unfortunate cases where a child somehow or other slips through the net, are only too well aware that every social worker seems to have about 103 cases each, and how on earth any more could be accommodated is something that we are going to have to look at very hard, and you have drawn our attention to it. Have you been able to make any reliable and detailed estimates of what this would all cost in terms of extra staff, extra money, training resources and so on? How will the Bill be properly implemented unless a lot more is spent, and have you any idea how much money that will be or where those resources could come from?

Mr Collingridge: The short answer to your question is no, we have not done the detailed work. We have started in the last couple of months to talk to the Department for Constitutional Affairs and Department of Health about what the areas are. I think our response mapped out some of the issues. In the last few weeks we have been looking at what the likely demands through the adult protection system are, etc etc, but we have got a very long way to go at this stage. So we are just mapping out what are the various factors that we need to put into the equation, and we have now identified groups of people that can start to do that work.

Q455 Baroness Knight of Collingtree: Am I right in thinking that the same people who will be called upon to implement the welfare sections in this Bill are already pretty well overworked as it is?

Mr Collingridge: You are quite right. That is a major concern, and if the adult protection arrangements that have started to come in start to bear down and

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you have this as well, then, yes, there are lots of opportunities for increased demands, and we do not know how we will meet those at the moment.

Q456 Baroness Knight of Collingtree: Are you ready to try and bring in some regulations within your own departments to make sure that certain sections of your department are not going to suffer by having a sudden movement of social workers away from them?

Mr Collingridge: One of the issues is that there are not duties under this Bill for local authorities to act under it. I think that is even the case at the moment with adult protection, except for a more general duty. So you will find, as you go around the country, very different responses to the same set of policies. We have that at the moment with the current Court of Protection arrangements. My authority in Hampshire has quite a well developed system; John's next door, until recently, did not do very much. I think unless there is adequate resourcing, and it is going to have to come not from local taxation but centrally, then I think authorities will decide probably not to implement parts of this Bill effectively because they cannot divert resources from, for example, facilitating early hospital discharge.

Q457 Baroness Knight of Collingtree: Of course, there is not a lot of point for us in this Parliament passing Bills that have sections within it which cannot be implemented, which might be a difficulty. Since you raise the question of the Court of Protection proceedings, this does really raise another cost implication. Do you think that the costs of that should be met from central funds, and do you think that Legal Aid should be called in to help with the cost of other parties?

Mr Collingridge: We do think that, yes, local authorities should be assisted with the legal costs of doing that. We have had a look, for example, in our own authority about the costs of one case, and if you get a complex case it is £7,000 to prepare it and, perhaps, £15,000 or more to go through the full legal system. We have got two of those at the moment, and that is more than the cost of a social worker each year. When you start to look at the implications they are quite significant and I do not think that local taxpayers can be expected to meet all those costs.

Q458 Baroness Knight of Collingtree: It certainly is emerging that you are as concerned as we are about this matter. Finally, could I ask you whether in preparing the Bill the Department for Constitutional Affairs has consulted either adequately or inadequately with the local authorities on this whole question?

Mr Collingridge: They have consulted with us. It is not adequate yet. We have had some initial discussions with them about the resource implications. At the end of August they issued a request to map out the information implications in terms of publications, and we found that perhaps up

to 50 publications might need to be altered—five or six substantially. In terms of anything else we have not really begun the process.

Q459 Baroness Knight of Collingtree: Is it recognised that this is only the beginning?

Mr Collingridge: Yes.

Q460 Baroness Knight of Collingtree: So further consultations are actually scheduled?

Mr Collingridge: I have spoken to the people and yes, they have given an undertaking to meet with us to work out in more detail the implications. That is particularly dependent on, I think, the report of this Committee and what exactly are the implications on and the expectations of local authorities.

Q461 Huw Irranca-Davies: I have listened with interest to the immediately preceding comments in respect of the Bill as it stands now and the impact on resources. If, to go back to the previous discussion, we were to look at the much more strengthened, central role of the rights of citizenship and so on, you must have put some thought to this as to the impact on resources of much more central, much more focused rights of the individual?

Mr Dixon: I think it would have some greater resource implications but I think it would be more that it would be underwriting the change in public policy that I think is happening already and which I think needs to be given an additional push. It would be very difficult to quantify.

Q462 Huw Irranca-Davies: So you anticipate those demands will become apparent regardless of what we put on the face of the Bill?

Mr Dixon: Yes. I think, to some extent, that affects the whole of this Bill. For example, in relation to Court of Protection work, Hampshire has started to do this work on Court of Protection, obviously, before this Bill has been enacted, and we have done too. It is because there are changes in expectations that we have got to respond to anyway, and the issue about adult protection has become a very major issue around the country. Again, without proper resourcing I think it is important that it is brought within the legal framework.

Q463 Mr Burstow: It is that point I wanted to go back on, the whole question of adult protection. Two or three years ago now the guidance was issued by the Department of Health *No Secrets*. Can you tell us what assessment you have made of the implementation of that guidance by local authorities? Are we still at the stage of codes of practice and training or are we now at the stage of having procedures that are actually having a reaction on the actual delivery of service and in dealing with abuse in care settings?

Mr Collingridge: My conversations with my colleagues around the country on this issue over the last week have revealed that there are quite different responses from authorities. My own and Herefordshire (who have just agreed to take the lead on this in our ADSS) have got some well-established

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guidance and local overview committees, practices and training in place. Other places have not really begun to implement it very substantially. It is not a matter that, at the moment, is regularly reported on to the Department of Health. As far as I am aware, there has been no particular inspections. So, frankly, we do not have, as yet, the overview. We would expect some time in the new year, with our new committee ourselves, to have a bit more of a feel, but it does feel a bit patchy at the moment.

Mr Dixon: Could I just add that we do feel bothered that after *No Secrets* had been launched it has tended to slip a bit out of the public eye. I am Chair of the Adult Protection Committee in West Sussex and we have quite significantly taken action in this area, we have had a number of adult protection investigations; it was on the television about a care home in West Sussex, an independent care home, last week and automatically the National Care Standards Commission picked it up and referred it to an adult protection investigation. So there is a lot of activity going on around this.

Q464 Mr Burstow: Are there any ways in which this Bill could help facilitate the roll out of *No Secrets* and the strengthened implementation around the country?

Mr Collingridge: There are. We have heard some lobbying and I think you have probably heard it too—suggestions that local authorities should have statutory duties to intervene. I believe, for example, in the general authority, when that has not been working terribly well or there is conflict, perhaps there is a role for local authorities there. You can certainly think of issues around that area where we should have stronger powers to intervene, and perhaps a duty.

Baroness Fookes: I do not have a clear picture of precisely what additional resources would be needed. Could you reduce it, as it were, to one local authority, one social services department? Would you need X number of additional social workers? What would be the cost per year and how is this going to be sold not to the Department for Constitutional Affairs but to the holder of the purse strings, the Treasury?

Q465 Baroness Barker: I have an additional question that follows straight on from that. Does the way in which social services departments relate to different client groups in different ways have an impact on the quality of the service? Does that have a very significant impact for a detailed Bill that covers very different client groups?

Mr Collingridge: As I said before, we cannot give you detailed numbers. I can tell you, for example, in Hampshire how many social workers we have got.

Q466 Baroness Fookes: That is what I want to know. For a particular authority.

Mr Collingridge: I have my statistics here in front of me for Hampshire County Council social services. For example, we have got 200 managers of various sorts, 650 social workers and another perhaps just under 3,000 field workers of various sorts—support

workers, home care workers. Plus, of course, you have got a whole tranche of people in the independent sector which I have not counted there. All of those people will need a basic level of training. Then, of those 650 social workers, if you are going to have to allocate particular adult protection cases—and we would expect demands to go up over the next few years—you might be able to factor in after a bit of research how much extra demand, but I cannot tell you. That is the baseline from which we are working at the moment in a total population in Hampshire of 1.2 million. Those kind of figures I have just given you, I can do more on that, but just to emphasise, Hampshire is one of the wealthiest county councils and, therefore, our numbers are relatively low in comparison to more metropolitan areas. That gives you a ballpark figure of where we are starting from.

Q467 Baroness Fookes: How many additional social workers, for example, might you be thinking of?

Mr Collingridge: We do not have a figure to put on it at the moment.

Mr Dixon: For adult protection an authority of the size of about half-a-million to one million people might have appointed about three additional social workers. It is not a vast amount. It is certainly affordable. It is, I hope, not so much that it would scare the Treasury.

Q468 Baroness Fookes: Are they there to be called upon? I thought there was a shortage of social workers.

Mr Dixon: There is.

Mr Collingridge: The recruitment and retention of social workers is a major issue. The Department of Health has been engaged in some work nationally to try and raise the profile.

Q469 Baroness Fookes: Even if you have the money it may not necessarily be easy to get the bodies?

Mr Collingridge: That is right. There needs to be a whole strategy around this. If I can just add as well to the issue about figures: I looked yesterday into how many adult protection referrals Hampshire had had. We had 80 in the first six months of this year. So that perhaps gives an indication of the size we are looking for.

Q470 Mrs Humble: Of course, it is not just social workers, it is your trainers, it is the administrative staff, it is the back room people who make sure the social workers can do the job.

Mr Dixon: Absolutely.

Q471 Lord Rix: Could I add to that? You mentioned independent agencies; I presume you mean voluntary bodies, I presume you mean parents, you mean carers, etc. They have all got to be added to the bill, too, in some way or another.

Mr Collingridge: Yes.

Mr Dixon: An adult protection committee now comprises about 20 different organisations, including voluntary organisations, including a range

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of statutory organisations and others. Could I answer the other question about the impact on different, what we would call, client groups? I think that is a very important point because we do provide a differential level of service to different age groups and people with different ranges of need. I think part of, as it were, our bid today is to be saying that this is a group of people who have tended not to get their fair share of the resources that there are going because their profile is lower. I think it is important that we should address that because there is a groundswell of need and a groundswell of opinion that we should move to assist them.

Q472 Baroness Barker: Following on that point, in the additional resources you are talking about, what would be the impact of Directors of Social Services to act as court appointed deputies, able to take welfare decisions for people who lack capacity? Could you answer that in light of the different and changing financial interests of charging policies which your departments are likely to be entering into?

Mr Collingridge: First of all, I think possibly many more authorities are going to have to pick up on the financial issues and have receivership units like, for example, Hampshire has. That costs us about £120,000 a year, of which we get back some money in charges. Secondly, there will be additional social workers for cases. I think you will have to have an individual person allocated to keep a close eye on the people for whom we have powers. Thirdly, of course, there are the legal costs and administration. We may need some additional administrative committee-like committees to oversee implementation—I do not know. There is one other issue which you, perhaps, were not expecting me to say on this, but in our discussion with the Department for Constitutional Affairs they talked about not the Director but, perhaps, people lower down in the structure having the legal power. We have got some concern about that; we think perhaps it should be the statutory function of Director who then delegates down, but certainly some of the thinking was perhaps to give the legal powers to a manager or even a social worker, and we are not terribly happy about that. That is the first part of your question. I cannot remember what the rest was now.

Q473 Baroness Barker: I wanted to focus particularly on charging policies and potential conflicts of interest. If I might add to that, what are the implications for this work when you are increasingly involved in joint planning of services with PCTs, for example?

Mr Dixon: Clearly, we need to think through what the implications would be for charging, but local authorities are very used to charging where we can because, otherwise, we are not going to be able to provide services for others who are in need of them. So where that is feasible and appropriate we want to explore that possibility as part of the development of the codes of practice.

Q474 Baroness Barker: How would you deal with conflicts of interest?

Mr Dixon: I think, to come back to the point we made at the very beginning, we have a clear responsibility to receive tax, to raise taxes locally and to try and square the equation in terms of the way we spend the money in relation to meeting our legal obligations and, indeed, our moral obligations. We need to establish advocacy and support for families and for service users to balance out what is that evident conflict of interest between us. The executive, whether it be a local government executive or national executive, always has that conflict of interest between resources and what we spend. It is the job of advocates, as it is the job of families, to be unconcerned about the resources but to be concerned only on the need. We need to have somebody who will come forward who will tell us also what that need is, so that we can hopefully do better at balancing that equation, but is a perennial problem that we live with.

Q475 Lord Pearson of Rannoch: Forgive me, but should that be up to a director of social services?

Mr Dixon: I think there is an issue there. I think there is a potential problem. On the other hand, we do, not infrequently, intervene in people's lives whether it be children or whether it be adults where other people who would be expected to undertake those responsibilities fall down. So if somebody has a general authority and is abusing that in some way, or there is an adult protection issue around an LPA then we would expect to intervene because somebody needs to do so. There is a principle here, in the Bill, of the least intervention in people's lives, and that is very important.

Mr Collingridge: Your question prompts me to think about some of the new arrangements that have come in recently about scrutiny and overview committees. Our one in Hampshire has just reminded me recently that they could scrutinise what I do, and there is a whole new set of relationships and functions in local government whereby the executive is called into account by other groups of elected members. So that offers a possible check or balance.

Q476 Baroness Knight of Collingtree: Coming back to a point you made just a few moments ago, in your submission to us you say at one point "We would like to know what proposals are being developed to enhance access to these services through the voluntary and independent sector, including the resources made available." Was that just a cry in the wilderness or were you actually hoping to get an answer there? If so, from whom?

Mr Dixon: That is back to the advocacy question. I think it is not a cry in the wilderness—

Q477 Baroness Knight of Collingtree: You anticipate getting an answer at some point?

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Mr Dixon: Yes, indeed.

Q478 Baroness Knight of Collingtree: From whom?

Mr Dixon: Anybody who is prepared to give it!

Q479 Mr Burstow: I wanted to come back to this issue of conflict of interest. It is really central to the part that local authorities and social services departments will play in giving effect to this legislation. Are you saying to us today that you have a clear idea of how you would separate out your responsibilities as a substitute decision-maker for an individual who lacked capacity from your responsibilities both as executive and scrutineers of your activities in carrying out your fiduciary duties to your ratepayers, or your council taxpayers? They are two completely separate things. If one overweighs the other, and you act in the interests of the ratepayer, you may well means-test someone and charge them, dispose of their assets in circumstances where, in fact, if they had capacity, they may well have wished to contest the argument and, indeed, argue that they had, for example, continuing care rights that were not being properly discharged. How do you square that circle? Can you square that circle?

Mr Dixon: No, you cannot square the circle. It is a continuing tension and it is one that we live with on a daily basis. Social workers take decisions, managers take decisions, and I, along with our elected members, oversee those decisions on a constant basis. I think it is impossible to take that tension and that task away from any executive. You always have to balance out the question of meeting need with rationing the resources that are required to meet that need.

Q480 Mr Burstow: With respect, if I can come back, I think the problem here is you are talking about the dilemma of an institution, like a local authority, having far more need than it can possibly resource. That is one issue and that is a tension that, of course, should remain with you. However, then there is the responsibility that this Bill can place upon you of acting as the person who lacks capacity and taking the decisions for them. How do you resolve having to act in their best interests at the same time as acting in the best interests of the council?

Mr Dixon: I think it is a conflict of interest. It is better in many instances for us to come in in an investigatory capacity rather than to have it on a long-term basis. Sometimes, in default of anybody else, we have to step in.

Q481 Chairman: The situation that you are now describing is one which is covered by common law. This Bill, as we said earlier, puts into statute what is now under common law. Will it make that tension that you describe easier or harder to resolve?

Mr Dixon: I think it does make it easier because it is about laying down further what it is that is expected of us.

Q482 Chairman: And there would be a legal framework for you to work within, would there not?

Mr Dixon: Yes.

Q483 Lord Rix: How would you see yourself as intervening in the case of a person who is deemed to have capacity but goes on making unwise decisions? How would you protect that person and how would you protect the parent or the carer if they reverse that decision from, say, a civil action?

Mr Dixon: I think that is a very difficult question. Enshrined in this is the right for people to make unwise decisions and I think that is very important because who is to say what is a wise or an unwise decision. It is the case that family disputes constantly centre around how people spend their money, how they spend their time, children and adults and so forth. We need to be very careful about how we step in to second-guess other people. I think this is where we would come back to this question of advocacy. Often we are swayed by very pragmatic considerations and may miss out on some of the more ethereal considerations that people want to take or maybe the spiritual considerations that people would take into account. Equally, families will support their loved ones in a certain way but may be very anxious about the consequences of them exceeding certain expectations or taking certain risks. I think we would come back to the importance of advocacy in providing a statement about what the individual thinks. This is not an area where things can be cut and dried, it is an area which comes down to the individual and their family.

Q484 Lord Pearson of Rannoch: One accepts that, but surely one part of the answer to the dilemma you have very honourably exposed, being both the executive responsible for the money and also having to do your best for the mentally incapacitated person, should be that the balance of who is appointed as a deputy or an advocate or whatever should perhaps move more towards the family and away from the professionals. That must be different in every case.

Mr Dixon: Yes.

Q485 Lord Pearson of Rannoch: It is only part of the answer.

Mr Dixon: I agree. I do not think it fits well with any professional undertaking that role.

Q486 Lord Rix: This question arises out of the blue. In Canada there has been quite a lot of discussion about the title of a Mental Incapacity Bill. You have talked a great deal about supported decision-making. Would you like to follow the Canadians and perhaps change the title of this Bill to Supported Decision-Making Bill?

Mr Collingridge: I have been influenced this morning by hearing from the Department of Constitutional Affairs, so that would be very difficult. We have not actually discussed that matter.

Q487 Lord Rix: But to a certain extent it would support your contention.

Mr Collingridge: It would go along with those lines, would it not?

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Q488 Lord Rix: Indeed.**Mr Dixon:** As I understand it that was the original working title of the Bill. No doubt it could be changed in that way.**Q489 Mrs Browning:** In these hard cases you have to deal with and exercise your powers for people without capacity how frequently do you come up against trust law and does it help or hinder your ability to take decisions?**Mr Dixon:** We do come across it from time to time, but in my experience it is pretty rare in that most people who we deal with do not have the sort of assets which would fall within that ambit at all, but it does happen.**Q490 Mrs Browning:** Does it help or hinder you, trust law as constituted at the moment?**Mr Dixon:** I cannot recollect any occasion where I have experienced a legal problem on that.**Mr Collingridge:** I would be very happy to go back and ask my staff, but I do not know of any, it has not come across my desk and I am the manager who manages the receivership unit.**Mrs Browning:** In a way trust law is used by people who do have assets in order to try and secondguess what somebody will need later on and in a way it is very similar to some of the arguments we have been talking about in respect of this Bill.**Q491 Chairman:** I think we have reached the point now where we have some other witnesses to see. Maybe you would be kind enough to write to us in some detail on that last point. You have touched on it in your previous answers but it would be helpful if you could write to us. We are extremely grateful for your attendance. Thank you very much indeed.**Mr Dixon:** Thank you.

24. Supplementary memorandum from the Association of Directors of Social Services (MIB 1213)

This submission supplements the oral evidence session on Tuesday 14 October 2003 (Questions 1–6 were covered in oral evidence).

GENERAL AUTHORITY

7. *Are you satisfied with the definition of the General Authority and should its exercise be monitored?*

- (a) The definition of the General Authority is not wholly satisfactory. This is in part due to concerns about other parts of the draft Bill to which Clause 6(6) refers and which provide the context. For example, as we said in our oral evidence, it is our view that the Bill should strengthen its emphasis on “P” as a citizen, whose needs and wishes are at the centre of the process, and who has access to a range of decision making support processes eg advocacy. If this formed part of the explicit framework of the Bill then some of the concerns about the scope of the General Authority would be alleviated.
- (b) In addition, the phraseology of Best Interests in Clause 4(4) “if the person reasonably believes that what he does or decides is in the best interests of the person concerned” and of the General Authority Clause 6(1) “it is lawful for any person to do an act when providing any form of care for another person” are very broad. Following our written submission to the Joint Committee in September we have become increasingly aware of concerns from service users, in particular those with learning disabilities, who are concerned that the General Authority is something of a “carers charter” and could in practice undermine the progress made in person-centred planning and service provision that has been achieved in recent years. We do not have an alternative form of wording to suggest, but at the very least the Code of Practice would need to make the safeguards explicit.
- (c) As we understand it, a significant purpose of the GA is to legitimise actions that are probably already taking place, and to support the wide ranging inputs from a range of family, friends, neighbours and professionals in their dealings with people who lack capacity.
- (d) The potential scope for monitoring is huge, and it is probably neither desirable or feasible for the State to have a role in the comprehensive monitoring of the use of the General Authority. This is not a matter that we have considered in depth, but there are current examples of good practice that could be developed eg keeping a unified record of health and social care contacts in a log in the person’s home. There is a good case for requiring records of the use of the General Authority in financial matters. There are, however, situations when there would be potential benefits in proactive monitoring eg where it is suspected that there is exploitation of “P”, or where “P”’s interests are being harmed by the conflicting actions of parties under this section. In these situations reference could be made to Local Authority Social Services’ adult protection arrangements. Guidance on these matters could be addressed in the Code of Practice.

- (e) It must be emphasised that Local Authorities have not been resourced for the additional responsibilities given them under the “No Secrets” guidance, and are not in a position to undertake additional responsibilities effectively without further resources. The ADSS would wish to engage in further discussions with the Department for Constitutional Affairs and the Department of Health regarding this.
- (f) The final issue we would like to raise in this section is the interface between the use of the General Authority and arrangements for Appointeeship (and its monitoring) made by the Department of Work and Pensions. The current proposals in the Bill and the Explanatory Notes are largely silent on this issue. We would like to see some proposals of how these powers work together, and the requirements for the effective monitoring of Appointeeship.

LASTING POWERS OF ATTORNEY AND ENDURING POWER OF ATTORNEY

8. *We note your concern about cases of possible abuse of LPAs. What should be done to monitor them to prevent abuse? And what should be done to prevent abuse of existing EPAs if the Bill is enacted?*

We make the following suggestions:

- (a) A requirement for the registration of all LPAs/EPAs, and that their authority cannot be recognised without the production of the relevant certificate.
- (b) Annual reporting on the use of powers (as is the case currently with Receivership Orders).
- (c) Referral by the Court of Protection to a Lord Chancellors Visitor in cases of concern.
- (d) National standards of practice for Lord Chancellors Visitors required to carry out these duties.
- (e) Where sufficient grounds of concern are identified, a requirement to refer to local adult protection arrangements for a co-ordinated multi agency response.
- (f) A statutory duty of Local Authority Social Services Departments to intervene when there are reasonable grounds to suspect abuse.
- (g) There is a need to ensure that there are robust arrangements in place in each Local Authority, adequately resourced by the Department of Health.
- (h) Powers to transfer the LPA/EPA to another suitable person or agency.
- (i) There needs to be more research on the nature and extent of abuse in these areas to inform practice, including guidance on the factors that may indicate abuse, and effective methods of intervention.

John Dixon

Chair of ADSS Disabilities Committee, and
Director of Social Services, West Sussex County Council

Graham Collingridge

Member of the ADSS Mental Health Strategy Group, and
County Manager (Mental Health Strategy) Hampshire County Council

25. Memorandum from Denzil Lush, Master of the Court of Protection (MIB 1049)

AUTONOMY AND PROTECTION

1. I support the broad thrust of the Bill, but I think it's weak in terms of protection. This can be remedied fairly simply with little need for extra resources. Principally, what is required is a change in emphasis in the introductory clauses, and to extend the offences of ill-treatment and neglect to cover financial abuse.

2. Mental health legislation in England and Wales has traditionally oscillated between patient autonomy and self-determination, on the one hand, and benign paternalism and protection, on the other (*qv* Clive Unsworth, *The Politics of Mental Health Legislation*, Oxford University Press, 1987). Striking the right balance is about as achievable as discovering the philosopher's stone or the holy grail.

3. The Law Commission's draft bill, which was published in 1995 and forms the basis of the present Mental Incapacity Bill, was something of a high-water mark in terms of autonomy. Since then, the pendulum has swung the other way, towards greater protection and the individual's right not to be abused.

4. I don't believe that, when it published its report on *Mental Incapacity* in 1995, the Law Commission was fully aware of the extent of financial exploitation, particularly affecting the elderly mentally infirm. Certainly, the more important surveys on abuse have postdated that report. But, even if it was aware, it failed to address the problem by providing adequate, private law safeguards.

5. Although its private law protection was weak, the Law Commission's public law proposals were quite robust. These largely replicated the Children Act 1989, though it has to be said that, unlike mentally incapacitated adults, children are rarely the victims of financial abuse. In any event, the public law proposals were jettisoned by the government in *Making Decisions* (1999), because, I assume, they were too expensive.

So, the current draft Bill, so far as it has inherited the Law Commission's recommendations, has already been stripped of the safeguards that would have gone some way towards striking a more even balance between protection and autonomy.

6. The offences of ill-treatment and neglect, described in clause 31 of the draft Bill, seem to relate solely to physical ill-treatment. If the legislation is to have any teeth, the government needs to make it clear that the financial abuse of people who lack capacity is also an area of zero tolerance. Some would argue that the existing criminal law is sufficient in this respect. I'm not sure I agree.

7. There are a number of well-intentioned statements in the first few clauses of the bill that should be included in a code of practice, rather than be enshrined in statute and thereby given greater status than they deserve.

8. For example, clause 2(2) provides that, "a person is not to be treated as unable to make a decision merely because he makes an unwise decision." There is nothing new about this statement. It has been part of English common law since at least 1850, when the then Vice-Chancellor came up with an almost identical formula. I agree with it in principle, but, if someone makes a continuous series of unwise decisions, should he or she be denied the protection the law provides for people who lack capacity?

9. Similarly, clause 3 restates the common-law principle that "a person must be assumed to have capacity unless it is established that he lacks capacity," but it over-simplifies the matter, and potentially favours abusers by not allowing the burden of proof to shift in appropriate cases.

10. For example, if an 85 year old woman with vascular dementia gives a door-to-door salesman, whom she has never met before, a cheque for £5,000, the onus should shift to him to prove that she had the capacity to understand the nature and effect of her actions when making a gift of that size, rather than there be an automatic presumption that she was capable of making the gift.

11. In *Re W (Enduring Power of Attorney)* [2001] 2 WLR 957 it was held that Mr Justice Hoffmann had inadvertently shifted the burden of proof in his important decision in *Re K, Re F* [1988] 1 All ER 358, where he set out the degree of understanding an individual needs in order to execute a valid enduring power of attorney. I understand that in the last month or so, in *Williams v Williams*, the judge intimated that *Re W* had also been wrong on the burden of proof. As you can imagine, if judges of the calibre of Lord Hoffmann can get it wrong, this is a complicated, controversial area, which needs to be considered very carefully.

BEST INTERESTS

12. I believe that anyone who acts for an incapacitated person (whether as an attorney, a deputy, or under the general authority to act) should be bound by various general obligations and, depending on the nature and formality of their appointment, a number of more specific duties.

13. By general obligations I mean, for example:

- to act reasonably;
- to act diligently;
- to act honestly and in good faith;
- to act within the scope of his or her authority;
- to limit interference in the life of the person without capacity to the greatest extent possible;
- to protect him or her from abuse, neglect, and exploitation;
- to respect and advance his or her civil liberties and human rights;
- to provide such assistance and support as is needed;
- where appropriate, actively to help him or her resume or assume independent or interdependent living;
- to involve him or her in all decision-making processes to the greatest possible extent;
- to encourage such participation and to help him or her to act independently in the areas where he or she is able;
- to encourage him or her to exercise whatever skills he or she has, and wherever possible to develop new skills;
- to exercise substituted judgment by respecting and following his or her wishes, values and beliefs to the greatest possible extent, so far as these are known or can be ascertained, and will not result in harm or be contrary to his or her best interests.

14. This list is by no means exhaustive, and one could add a number of other fiduciary duties—such as not profiting from one's position, keeping the incapacitated person's funds separate from your own, avoiding conflicts of interests, and the duty of confidentiality. A person acting for someone who lacks capacity also owes him or her a duty of care, which varies according to whether the attorney, deputy or other agent is acting gratuitously, or professionally for remuneration.

15. More specific duties would depend on the nature of the appointment or the form of intervention ordered by the court. They include, for example, making an inventory, giving security, filing annual accounts and reports, etc.

16. Clause 4 of the Mental Incapacity Bill provides, in subsection (1), that any act done for or any decision made on behalf of a person who lacks capacity must be done or made in the person's best interests. Subsection (2) then goes on to provide a "statutory checklist", which sets out various criteria for establishing whether an act or decision is in someone's best interests.

17. This "statutory checklist" attempts to define the elusive concept of "best interests", but it only covers a limited range of the considerations I described above as general obligations, and I have doubts as to its overall adequacy and efficacy.

18. I am also concerned about the prominence "best interests" is given in the entire scheme of things, and the fact that it is too prescriptive. Everything seems to hang on it. For example, one of the few grounds on which an attorney can be removed is if he has acted, is acting, or proposes to act in a way that is not in the best interests of the person who lacks capacity (clause 21).

19. I realise there is a danger that presenting prospective substitute decision-makers with a list of obligations could deter them from acting, but, if they are not willing to adhere to a basic code of conduct governing acceptable behaviour, then perhaps it would be better if they didn't act. The Law Commission considered this in an earlier report, *The Incapacitated Principal* (1983), which led to the Enduring Powers of Attorney Act 1985. At paragraph 4.69 it said:

Accordingly we do not recommend that the attorney should be subject to a statutory duty to act. The problems that such a duty would solve would, we feel, be heavily outweighed by those it would create. And we are well aware of the risks of discouraging the acceptance of EPA attorneys. In our view, the prospects of a donor's affairs being well run after his incapacity are dependent not so much upon duties and sanctions but rather upon his choice of attorney at the outset.

20. I am not convinced that the Law Commission's stance is still tenable. In *Acting as Agent under a Financial Durable Power of Attorney: An Unscripted Role* (Nebraska Law Review 75, 575 (1996)), the author (Carolyn L Dessin) suggested:

Recently, however, concerns have been voiced that perhaps we have created an instrument of abuse rather than a useful tool. Sometimes the problems are as clear as wrongful misappropriation of the principal's property by the agent. Often, however, problems arise because the standards governing the behaviour of agents under durable powers of attorney have never been clearly defined. In many instances, those standards have not even been considered. Legislatures, courts, and commentators have often simply assumed the application of various bodies of law without careful reflection.

21. The term "best interests" doesn't feature in the Adults with Incapacity (Scotland) Act 2000. Instead, the Scottish Law Commission preferred to state various fundamental general principles, which now appear in section 1 of that Act. These principles, however, go little further towards creating a comprehensive code of conduct for substitute decision-makers along the lines I have described above.

22. In summary, therefore, I believe that, instead of imposing a duty to act in a person's best interests, there should be a comprehensive statement of the standard of conduct required of everyone who acts or makes decisions on behalf of persons without capacity, and if their behaviour falls below those standards it should be possible for the court to remove them as attorneys or deputies, or as the case may be, and if their conduct is criminal, they should face the prospect and consequences of prosecution.

CONCLUSION

23. I shall conclude my submission here for the time being, because, apart from considering whether there is a need for this legislation in the first place, the main issue for the committee to decide is whether the draft Bill has struck the right balance between autonomy and protection, and I wouldn't wish my comments on this fundamental issue to be weighed down by technical arguments on other less important aspects of the Bill.

August 2003

Witness: Mr Denzil Lush, Master of the Court of Protection, examined.

Q492 Chairman: Mr Lush, thank you very much for attending. Perhaps you would like to introduce yourself and then we can proceed.

Mr Lush: I am Denzil Lush. I am the Master of the Court of Protection. I have been in post for seven and a half years, since April 1996.

Q493 Chairman: Thank you very much. Your submission starts by saying at the very beginning that you support the broad thrust of the draft Bill, but you end by saying (paragraph 23) that the main issue before the Committee is whether there is a need for this legislation in the first place. Have you still any doubt about that need? Is not the key question whether, if there is a need, the draft Bill meets it? Or do you think the needs of people lacking capacity can be addressed other than through this legislation?

Mr Lush: I think perhaps you might have misunderstood what I was saying. I was saying at the end of the submission that the most important question before you is whether there is a need for this legislation in the first place. I assume you have had some people lobbying and saying you do not need it. If that is the first and most important question, the second is whether you have got it right in terms of the balance between autonomy and what we call protection. I have no doubt in my own mind that there is a need for this legislation. I think the current state of affairs particularly with regard to medical decision-making powers is unsatisfactory. My court only has jurisdiction over financial and property affairs. Just an hour ago I was finishing a hearing that largely revolved around where somebody should live, whether he should live in Blackwall or go and live in Birmingham. We cannot decide for him, but the money that we hold indirectly might have some implications on that.

Q494 Chairman: If there is somebody on a Protection Order and you have the ultimate responsibility under the Protection Order for finance but there are other decisions which will be taken, not by the receiver, to do with health, welfare and social care, you have no influence or responsibility for that at all, have you?

Mr Lush: No, not really, only the financial aspects.

Q495 Lord Rix: In paragraph 8 of your submission you seem to suggest that someone who makes a series of unwise decisions should be treated as a person who lacks capacity. Could you possibly expand on this? I follow this with a question about the presumption of capacity being set-aside. How would you suggest that could be possible?

Mr Lush: I think one of the problems here is the distinction between specific issue capacity and more general capacity. In the Court of Protection we deal with the big damages awards that come in for personal injury, criminal negligence, criminal assaults and so on. I reckon it is about 350 of these a year and they are for large sums of money. There have been three in the last 12 months that have produced formally just short of half a billion pounds, £496 million-worth of damages. Our client

group tends to be young men in their late 20s who have had road traffic accidents and usually elderly women of 85 plus, usually widowed, usually living in Bexhill or Christchurch and so on at the other extreme. One of our particular cases was where a young man had been awarded £2 million damages. He came in with a wish list. He wanted to buy a five-bedroomed house in north London for just over £1 million. Bear in mind that he is a single man with no dependents, although I think he wanted a chef to take one of the rooms. He wanted a villa in Turkey where he had family connections, a villa in the US, a top of the range limousine with a chauffeur, an executive box at Highbury Stadium and a Rolex watch. I suggested to him that when a damages action is completed the court usually says you can have a little bit of a celebration, a little bit of a splash, so you can have the Rolex watch for £5,000. He then went down to a jewellers and chose it and the receiver paid the bill, but three days later he had traded in the Rolex watch for £3,000 and used it to fund a drag habit or something like that. What I am saying there is that there would be a series of unwise decisions. He might have the actual understanding or capacity to make each of those decisions to buy the £1 million house in north London, but there is a general lack of capacity rather than a specific issue. We had a similar problem at the other end of the spectrum with a lady who lived in Surrey who was taken to the cleaners by some people who were selling cleaning materials, I think they were called "Nottingham Knockers". She paid over the top for dusters and cleaning materials and so on. She was then duped by her gardener in whom she had a lot of confidence who managed to take some £16,000 from her by various means and then she was persuaded to give an enduring power of attorney in favour of a lady who lived nearby who was married to a property developer. She then sold the property to her husband, he developed it and sold it at £600,000 profit for himself. These are the sort of cases in which there is on-going incapacity. It is all very well saying there are specific cases of capacity and the ability to make particular contracts or decisions, but there are cases where people have on-going incapacity or they would make a series of judgments or decisions that were totally disastrous to them.

Q496 Lord Rix: How would you add up the number of adverse decisions which could be made before you actually could intervene, especially if there is a problem of immediacy? Let us suppose a person was averse to the treatment by the local dentist and they were suffering the most appalling toothache but refused to go. Then they refused to go to the doctor the next day because they did not like doctors and so it went on and there were a series of health damaging decisions made which really have to be remedied very quickly; how would you deal with that?

Mr Lush: I think one would probably intervene, but I think really what has happened here is that the Law Commission and later the people who drafted the Bill are using that expression—it is an old expression that was used in English law—as a means of saying the outcome of the decision is not particularly

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important because we are going down the functional capacity route. What I am saying is that that is fine for specific functions, but there is acknowledged to be general incapacity, not necessarily global and I do not think this is fully recognised in the draft Bill.

Q497 Chairman: You mentioned the figure of almost half a billion for the value of awards. We hear of awards being made for £2 million or £5 million but that is converted to an annual sum. I believe it is true that most people do not live to collect the full amount as a result of the injuries which are the reason for the award. Is that correct?

Mr Lush: I am not sure it is entirely correct. There is no reliable research on the largest awards. Basically the damages awards are calculated on the basis that on the last day of that patient's life we should be in the process of spending the last penny or the last pound. If there is a lot that is left over then we have not done our job very well because we have not provided them with the resources and accommodation and the care that they deserve. If we run out of money when they are ten years before death then we should be held responsible.

Q498 Baroness Fookes: In paragraphs 13 and 15 of your submission you have a list of check-list items. Are you suggesting that they should replace the check-list in the draft Bill or could some of them be devolved to the Code of Practice? I am not quite clear.

Mr Lush: I think probably what I was saying was that best interests covers an enormous range of different activities. I am slightly nervous about the fact that this draft Bill has limited the check-list that people have to go through to just one or two particular requirements. What I was looking for from all substitute decision-makers was a general standard of good behaviour and conduct and a realisation of what their obligations were to the person on whose behalf they are acting. I would be quite happy to replace the best interests criteria or if they are in a Code of Practice so be it, but I would not feel too happy about them being relegated to small print, if you are with me. I think a lot of the problems are to do with the fact that people do not really have their duties and obligations spelt out and we need to know what is acceptable and what is not.

Q499 Baroness Fookes: It is difficult, is it not, to have a totally comprehensive list if one is going down that route?

Mr Lush: Quite right.

Q500 Baroness Fookes: How would you deal with that particular problem if you want things spelt out more than they are?

Mr Lush: We have exactly the same dilemma with the best interests case. By no means is that fully defined in those four criteria. It is a question of parliamentary draftsmanship.

Q501 Mr Burstow: Talking of parliamentary drafting and relevant wording, I wanted to come back to this concept of general incapacity that you

were describing just now and I wondered if you might be able to help us with any thoughts as to a formulation that could be incorporated into the draft Bill to enable us to capture that idea?

Mr Lush: The Court of Protection's jurisdiction is invoked when a person is incapable by reason of mental disorder of managing and administering their property and affairs. The mental disorder bit actually appears in the Mental Health Act, but nobody in a reported decision has ever come up with what incapacity to manage your property and affairs actually means. There was one judge, Judge Wilberforce, who said back in 1963 that it depended largely on the property and estate that you had to manage and administer. He was referring to an ambassador's widow who lived in the Holden Hills in Devon, in a beautiful Queen Anne mansion that would probably be worth £5 or £6 million nowadays and she had a stroke and she really could not communicate. What I think he was saying there is that where you have somebody with a property of that significance to manage and administer it is probably more problematic to do so than if somebody has just a £30,000 account in the Halifax Building Society which would be easier to manage. Then there are other considerations that were brought in by another judge that really meant taking advice, maybe a problem over financial management and weighing the advice in the balance and arriving at a decision in that way. There was a case called *Masterman-Lister v Brutton & Co* that was widely reported last year and went to the Court of Appeal. I do not think it has helped in any way because they were relying on the Law Commission's definition of specific function and capacity, which is what appears in this Bill, and trying to apply it to general capacity, which is "general ability to manage one's property and affairs". I do not think the common law has got it right. I do not know if it would be possible to come up with some sort of proper formula as to the capacity to manage one's affairs, but I would not like to shoot one off the top of my head right now.

Q502 Mr Burstow: Could you possibly come back to the Committee with some further thoughts on that?

Mr Lush: Yes. What in fact happened in *Masterman-Lister* is that I fed the judge some materials on that and there was a particularly useful decision based on an Australian case that was based itself on American rulings before it which was that it was quite a satisfactory definition of it.

Q503 Lord Pearson of Rannoch: Surely it is almost impossible to draw the line on this one between those who do have capacity and those who do not because we can all think of families who have in one way or another wasted colossal fortunes, one generation taking decisions which technically look as though they lack mental capacity, but one surely cannot do anything about that. Likewise, your example of the old lady who gave an awful lot of money to her window cleaner, if she is otherwise sane, surely it is a very difficult one to define in law, is it not?

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Mr Lush: Yes.

Q504 Lord Pearson of Rannoch: A fool and his money can be easily parted!

Mr Lush: There are two extremes. There is capacity at one end of the spectrum where understanding is everything and there is undue influence at the other end of the spectrum where a particular relationship is involved and there is a great grey area in between. I think essentially what I was trying to say in my submission is a lot of this is to do with burdens of proof and a lot of the burdens of proof really relate to unscrambling transactions that have gone wrong. I think, for example, the burdens of proof are not the same for different transactions. I was spectacularly reversed in a case called *Re W* a few years ago where I ruled that a person was incapable of creating an enduring power of attorney. I had some evidence from an eminent psychologist which said no way was she capable of creating an enduring power of attorney on 6 June, so I refused to register it and her attorney appealed and she was successful in her appeal. What the judge said was, "I did not need to be satisfied that she understood that she actually had the capacity to make it. All that I needed to be satisfied about was that she did not lack the incapacity to make it". That was a totally different emphasis on this and these are objections to the registration of enduring powers of attorney on the grounds that they are not valid. I think probably up until then we were objecting on a regular basis, but since then I think there are only two or three cases where an objection has been upheld on that basis. A lot of this burden of proof area is desperately complicated, but I think by looking into it and perhaps making sure that when things go wrong they can be unscrambled relatively easily, burdens of proof have a lot to play.

The Committee suspended for a division.

Q505 Mrs Browning: How serious is the problem of financial abuse with enduring powers of attorney in your view? You mentioned surveys in your submission, surveys of abuse, and I just wondered how accurate they are and why then you say that you are not sure you agree with those who claim that the existing criminal law is not adequate to deal with financial abuse of people who lack capacity. If I may, Chairman, just add a tail end of my own because it relates to a particular constituency case I have been dealing with, the Court of Protection actually have managed to restore money, but were unable to refer it for criminal prosecution because the person concerned was 98 and clearly could not be called as a witness. I just wonder how difficult it is to bring criminal prosecutions when the key witness lacks capacity.

Mr Lush: I think you have just answered the question you were going to ask, that particular part. I have gone down on record in the *Solicitors' Journal* on 11 September 1998 as saying that I think that financial abuse occurs in about ten to 15% of cases involving enduring powers of attorney. In fact the figure is one in eight, but I put it at ten to 15 because

that sort of sounded slightly vaguer. That was 1998 and I still adhere to that estimate, though I admit it is entirely a hunch and just an instinctive assessment. There is nobody who can possibly say that you have got, say, 39,421 people being abused at this very moment; nobody could possibly collect that data. Another problem is how do you actually define "abuse". If you were talking in terms of purely criminal behaviour, then I think probably the abuse level would be at 2 or 3%. If you are talking about unethical conduct of any kind, it is going to be much higher and that is the sort of figure I am talking about, the 12.5% being the one in eight. The largest abuse case that we have come across of an enduring power of attorney involved an elderly lady from Torquay who one lunchtime was invited to have a glass of sherry with the proprietor of the residential care home in which she lived and after two or three sherries gave an enduring power of attorney in her favour and a will and he then proceeded to raid her bank account and transfer it to a Swiss bank account in his own name. It was £1.9 million. We did in fact have a bit of a result and we managed to recover £1.3 million, but £600,000 he had spent. What is actually much more interesting is the abuse that occurs at the lower level, that threshold of where do you draw the line between acceptable and unacceptable behaviour. I had an application for the objection of an enduring power of attorney a few years ago where the objector was claiming that her brother, who was the attorney, was charging 31 pence a mile every time he went to see the mother. Now, the mother lived in Banbury and he lived in Evesham and the round trip was 90 miles, 45 miles each way, so that was £27.30 each time he visited his mother and he visited her three times a week, so that was £82. Now, as an attorney, there was absolutely no need for him to visit her that frequently and claim reimbursement for all business expenses. If he is visiting her as a loving son, you would not expect him to charge that sort of rate of remuneration, so it is those lower levels of abuse which are in fact far more interesting than the patently criminal ones. As far as surveys are concerned, I think you, Mr Burstow, mentioned or somebody mentioned *No Secrets* and that was in the year 2000 that that was published. There was a survey conducted by the charity, Action on Elderly Abuse, and it was published in the press quite widely in July 2002 and, according to that, one in three elderly people suffer from psychological abuse, one in five are physically abused, the same number are conned out of their savings and more than 10% are neglected and 2.4% are abused sexually.

The Committee suspended for a division.

Q506 Mrs Browning: Is your proposal to extend the offences of ill-treatment and neglect in this Bill likely to be adequate to cover the scenarios you have described to us? Also what sort of extensive monitoring system would you feel was appropriate to try and address some of these problems?

Mr Lush: I think the recommendations I was coming up with primarily were sort of just tweaking changes of emphasis in the private law/civil law side of things

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really to put right disasters and to restore people's positions they were in before they made a problem transaction or whatever. On the criminal side, I think it was you who said earlier on that a lot of the problem is that the star witness is the elderly person who has been abused and the police are reluctant to prosecute. Half of the abuses which occur involve family members and again we have this additional complication where it comes down to best interests and whether it is in the best interests of the old person for a family member to be charged, convicted and possibly given a custodial sentence. We did have one two or three years ago where a daughter and son-in-law were both attorneys under an enduring power of attorney and behaved appallingly. The son-in-law was given a custodial sentence, but charges were dropped against the daughter and I think that was the first time that I was aware that a family member had actually been given a custodial sentence for an abuse.

Q507 Baroness Barker: This is a question which you may not be in a position to answer now, and that is fine if you wish to write to us subsequently, but the question I would like to ask is given your experiences, with the practices of financial institutions (a) to what extent are they consistent or not, and (b) to what extent do they help to foster or to prevent situations in which financial abuse can happen? As a supplementary to that, given the huge changes that are taking place in the technology of finance at the moment, does that give additional cause for concern?

Mr Lush: The Irish Law Commission have come up with a paper fairly recently on the law and the elderly, looking at much the same sort of areas as you are looking at and one of the recommendations they are coming up with is that there should be a far greater responsibility on financial institutions to monitor accounts that involve old or vulnerable people, particularly perhaps joint accounts. I go along with that and I think there is an educational process and I think there is going to be a greater duty on them to do that. Something that is not in the public domain is that we had quite an interesting case last year which involved a woman who had two sons, one of whom was an attorney who took all of her savings, £74,000, and the other son then was appointed receiver and sued his brother to get the money back, but the brother was by then bankrupt, so what could he do? Well, this guy had a bright idea and he actually went to the Financial Services Ombudsman and the Financial Services Ombudsman held that the Alliance & Leicester had been under a duty to monitor strange movements from this account and in fact failed to do so and ordered the payment of £50,000 back to this woman's estate. So it is there, but it is not widely known and I do not think that case ever made it into the public domain, but I think there is a lot of scope for them to be educated and have special rules on protected accounts.

Baroness Barker: I am sure that would not be a matter for the face of the Bill now, but possibly for regulation.

Q508 Baroness Knight of Collingtree: This question deals with the point you made in your submission on autonomy and protection and the very first thing you said was that you thought the Bill was weak in terms of protection and this is a very major cause for concern. Now, throughout your submission you suggested that there was quite an easy way to get over this. You may not be able to answer it now, but I would be very grateful if you could give your own thoughts or suggestions as to how to get over this lack of protection. You also said that it can be remedied fairly simply with a little need for extra resources, so perhaps you could at least tell us what is "little" in that sense?

Mr Lush: What I meant was just tinkering with these burdens of proof, making it much harder for abusers by making it easier for burdens to shift so that the burden of proof is then on somebody who has taken advantage of an unreasonable transaction. Once you get down to trying to recover money civilly from people who have abused, it is a very lengthy process and there are enormous obstacles, so you could somehow make that easier and that would be a relatively cheap solution.

Q509 Baroness Knight of Collingtree: When you, in the same submission, said that that could be included in a code of practice, are you thinking along those lines?

Mr Lush: Possibly.

Q510 Baroness Knight of Collingtree: Because I could not quite balance up the two.

Mr Lush: Possibly the burdens of proof then could be dealt with in a code of practice, yes. You see, what happens is that the burden of capacity then shifts. You have someone, an elderly woman, say, 85 years' old, she gives £5,000 under mysterious circumstances and she is presumed to be able to do that. The burden should then shift to the person who has received that gift to say, "Well, no, she really knew and understood what she was doing", and certainly with wills and so on and the monstrous switchings of burdens. Now, this Bill is going to cover wills and it is going to cover gifts and things like that as well as other transactions and the rules are really very complicated and they have not really been given enough attention. I think simply to say there is a presumption of capacity grossly overstates the problem and complexities of it.

Baroness Knight of Collingtree: Perhaps in the interest of covering this very important point about protection we might ask Master Lush if he would consider this point very carefully and if he could give us any further information that would be very valuable.

Q511 Mr Burstow: Can I just pick up on one thought which is in the submission, which is this issue of duty of care that should be on those who are substitute decision-makers and whether or not you feel that the legislation as currently drafted does implicitly place such a duty and whether there would be an advantage in making it explicit on the face of the Bill?

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Mr Lush: I am not sure that it does. If you actually read through that legislation, the only people who are required to act reasonably are those under a general authority. That is the only time the word “reasonably” arises. Theoretically you do not have that with deputies and LPAs. I am sure they would act reasonably. I am also worried that actually I can only remove people who are not acting in the best interests and that does not necessarily enable me to remove somebody who is incompetent because you have got this very narrow test of what “best

interests” means. So you could have somebody who is appallingly incompetent in terms of providing financial needs and requirements but I am not sure I can get rid of them purely on the best interests test as laid out in the Bill.

Chairman: Thank you, that is very helpful. Would you be kind enough to write to us particularly on advance decisions, which we have not reached, powers of inspection and the extra powers you have referred to. That would be very, very helpful. Thank you.

26. Memorandum from Professor John Williams, Department of Law, University of Wales, Aberystwyth (MIB 564)

1. My reason for submitting evidence to the Joint Committee arises out of my professional interest in the area of social services law and in particular the law relating to vulnerable adults. I have published a number of articles on vulnerable adults in academic journals such as the *British Journal of Social Work*, *Journal of Social Work*, *Journal of Social Welfare and Family Law* and the *Criminal Law Review* as well as a number of essays in edited collections. In addition to my teaching at the University in Family and Child Law, and Medicine, Ethics and the Law, I also undertake professional training for social workers and other social care professionals for local authorities and the voluntary sector. I am a training consultant for the British Association of Services for the Elderly (BASE).¹

2. The draft Bill is welcome and very timely. Incapacity is a growing area of concern for social work practitioners and most feel uncomfortable working under the existing system. Whereas the common law on decision making for incapacitated people has served us reasonably well and facilitated decision making for incapacitated people, it is doubtful whether it contains sufficient safeguards to ensure that it does not violate the European Convention on Human Rights (ECHR), especially the article 8 right to a private life. The recent case of *Re F (Adult Patient)* illustrates the extent to which the courts have to go to provide adequate protection for those who lack capacity.² My comments concentrate on specific aspects of the draft bill; they are made in the context of general support for what the bill is seeking to achieve.

3. *The definition of legal capacity:* The definition in clause 2 quite properly develops the common law definition, but gives legal force to what has in the past merely been good practice (which anecdotal evidence suggest is not always followed). Sub clauses 2(2)–(5) are particularly welcome. However, one situation not covered by the definition are those cases, often abuse cases, where a vulnerable person probably does have capacity (it may be marginal), but is subject to undue influence by an abusing carer, relative or professional. The dilemma for professionals is that if the person refuses help and support, there is little that can be done because the law will deem them to have capacity. It is interesting to note that the heading for the section is “Inability to make decisions” rather than incapacity. Is it intended that clause 2(2) should include extreme (and I emphasise extreme) cases of undue influence? Would such cases come within clause 2(1)(c) and (d) as cases of inability to use the information or communicate the decision because of intimidation? Clearly the provisions of clause 1 mean that they would not unless it arose from an impairment or disturbance in the functioning of the brain or the mind. I would suggest that some thought be given to extending the remit of the bill to include extreme cases of undue influence, with the necessary safeguards included to make it compatible with the ECHR. This would require extending the definition in clause 1.

4. *Best interests:* Placing the best interests test on a statutory basis is welcome and will ensure some consistency in decision making for incapacitated people. It is essential that the contents of clause 4 are disseminated widely by health and social care professionals. Undoubtedly, this will be done by professional bodies and employers. The more difficult group to cover is the one consisting of people using the general authority under clause 6. Will such people, often informal carers, be aware of the meaning of “best interests”? There may be a tendency to understand it as paternalistic and always doing what is “sensible” when in fact the incapacitated person may, during a lucid period, made it clear that they do not want to do what is sensible. There needs to be widespread dissemination of the “best interests” test. I am not entirely happy with the term “best interests” as it does conjure up the image of paternalism. A less concise, but in my opinion a more acceptable term, would be “in the interests of promoting the human rights of the person”. This would suggest that a liberty based calculation has to be made which will embrace both the need to protect, but also recognise the individual’s autonomy. I accept that the individual’s autonomy may be seriously compromised by their incapacity; however it must still be part of the calculation.

¹ The views in this paper are my own and do not represent those of BASE.

² I enclose a copy of an article published in the *Journal of Social Work* which addresses my concerns on the decision in relation to vulnerable adult protection laws.

5. *The general authority:* Placing what de facto happens on a regular basis on a statutory basis is welcome and will provide protection not only for the incapacitated person, but also the person who has assumed the responsibility. My main concern is that in some cases this may well give a false sense of legitimacy to something that is inherently abusive. Will abusers be able to hide behind the general authority and effectively gain “lawful” authority for their actions? Again anecdotal evidence suggests that enduring powers of attorney and appointeeships are being used in this way. I appreciate that given the possible extensive use of the general authority, close regulation is impossible. The proposed criminal offence in clause 33 may reinforce the duty to act responsibly. However, I remain concerned that what is a well intentioned idea may in practice be used as an instrument of abuse. Is it possible to strengthen the safeguards? Should people using the general authority be required to keep very simple accounts? Is it possible for there to be a “light touch” (very light—I appreciate the resource implications) registration process for people using the authority?

6. *Advance decisions:* It is trite to say that this is an immensely complicated and sensitive area; there is a need to inject some legal certainty to protect patients and doctors. Obviously it is important that people are aware that the proposals are not just about life sustaining treatment but of more general application, although I suspect that such treatment will be the one that attracts media attention. In general the provisions of clauses 23–25 are good. My one reservation is the wording of clause 24(4)(c). Does this give too much scope for medical practitioners to override advance decisions? It is understandable that doctors may wish to save life or promote wellbeing (the recent case of Ms B illustrates this point). My concern is that the wording of that sub clause gives considerable scope for “rewriting” the terms of an advance decision, for example by stating that medicine has advanced since the advance decision was made and the patient would surely have wanted the treatment. Presumably such decisions by doctors would be subject to the Bolam test—would a responsible body of medical opinion have come to the same conclusion? This may undermine the effectiveness of advance decisions if it is interpreted widely by doctors. Firmer safeguards are required. A related point is whether advance decisions should be time limited during the capacity of the person; it may be sensible for people who still have capacity to update them (say every five years) to ensure that advances in medicine are taken into consideration. Alternatively, an incentive to update may be included whereby the working of clause 24(4)(c) could give doctors more scope to deem the advance decision to be non applicable after (say) a five year period. This would allow them to have greater regard to changed circumstances, namely new advances in treatment that the person could not have been aware of at the time of making the advance decision.

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Witness: Professor John Williams, University of Wales (Aberystwyth), examined.

Q512 Chairman: Professor Williams, thank you very much, you have been extremely patient in waiting. I think you heard about housekeeping at the beginning so I do not need to repeat that. If you would introduce yourself and then I will ask the first question.

Professor Williams: My name is John Williams. I am Professor of Law at the University of Wales (Aberystwyth), and I am head of the Department of Law.

Q513 Chairman: Thank you. As there is already a framework of case law that governs the area of mental incapacity, how does the draft Bill improve the situation? Do you think that Codes of Practice can be drawn up in such a way as to provide unambiguous guidance in areas that are not covered on the face of the Bill?

Professor Williams: I think in response to the first point about whether the common law is adequate, the common law is okay and I think in fairness to the judiciary they have done a very good job with very little to work on. I think there have been some very sensitive and very humane decisions by the judges, particularly in the 2000 case of *Re F*. I think the difficulty is if we leave it to the common law, we are in a situation where we are making it up as we go along. Increasingly complex issues come before the courts and previous case law does not really allow us a way

forward. I think this is particularly worrying since the implementation of the Human Rights Act where we are clearly dealing with issues concerning people's private lives, concerning their right not to be subjected to inhuman and degrading treatment, and yet the procedures that we have in place under the common law are not easily identifiable, they lack the element of predictability that really the European Convention expects us to have. I think a statute could provide greater clarity, would allow people to plan with greater precision for possible future incapacity and would, very importantly, incorporate procedural safeguards, because if you look at cases such as the *Bournewood* case, if you look at cases such as the *Re F* case I have just mentioned, I think in a sense you have resolved the immediate crisis, particularly in the *Re F* case, but the question is where do we go from here? Does she remain in the care home for the rest of her life? Does anyone think of reviewing the case, to think maybe we should remove the declaration? This is the problem with the common law. As I say, the judges have done a pretty good job. Butler-Sloss in the *Re F* case made it quite clear that they were filling in the gaps and that really this was an issue that Parliament should look at.

Q514 Chairman: On the question of Codes of Practice, these will be extremely important. Do you think they can be drafted in such a way as to provide the unambiguous guidance needed?

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Professor Williams: I think in principle, yes, the devil is always in the detail. One could look perhaps at the model provided by the codes produced by the then Lord Chancellor's Department over the last two to three years, I think that they actually provide a basis for going forward. What we do not want is a situation where decision-makers are inundated with printed material because we know what happens; they are busy people. If we had a series of codes we would have to target different codes for different groups. Again, the Lord Chancellor's draft codes did this. In particular, we would have to target people who may have incapacity. If we do that I think the codes will have a role to play. I think we will have to be cautious about putting too much into codes because too much soft law, in a sense, brings us back to where we are at the moment, you have got a very loose statutory framework and the bulk of the detail is in codes and really amounts to a soft law rather than a hard law. But as a lawyer I would say that.

Q515 Lord Pearson of Rannoch: In your opinion, do you think that the draft Bill is compatible with the 1998 Human Rights Act?

Professor Williams: I think on the whole the answer is yes. It clearly envisages intruding into, for example, the private lives of people who may have incapacity, but I think that it also complies with provisions of Article 8(2) of the Convention. It will, and I think this goes back to the common law, provide a clear statement of the law as to what can and cannot be done, so we will have the lawfulness. I think it is within the remit of Article 8(2) in terms of health, morality, prevention of criminal offences and so on. Very importantly, the third requirement, I think it is a proportional response. I say all that in a vacuum because to some extent it will depend how it works in practice. It will also depend on what is in the codes that are going to be produced under the Act. On the whole, I think I am satisfied that it will be within the Human Rights Act. I am reassured in that conclusion by looking at what we have at present, which certainly in my view does not comply with the Human Rights Act, tolerates financial abuse, tolerates physical abuse, and basically there is nothing that can be done. Again, the European Court have made it clear in the case of *A v UK*, for example, that the state does have a positive duty to protect particularly vulnerable people. In a sense, I think where we are at the moment is incompatible and I would certainly argue that if the Bill becomes law that it will be consistent with the Human Rights Act.

Q516 Mr Burstow: One of the themes running through today's evidence session has been balancing autonomy against protection, and in your submission you put forward the need for us to give some consideration as to how the test of capacity is actually put into practice, particularly in circumstances where abuse is believed to have occurred. Could you tell us perhaps a little more about how you think clause 1 might be extended to include extreme cases of undue influence over

capable but vulnerable adults. What would be your formulation to enable the law to take into account those circumstances?

Professor Williams: At the outset I think I fully accept that it is a very difficult piece of drafting if you are going to incorporate people with capacity but who are vulnerable. I think we might have a model in the draft Bill proposed by the Scottish Executive, their vulnerable adult protection laws, in terms of defining vulnerability and then saying that we will intervene but we will not intervene if the person refuses consent, except where, they refer to the person being "mentally disordered" and by that I think they probably mean incapacitated. The second reason for compulsory intervention without consent would be the person has been pressurised by some other person, so it incorporates the notion of undue influence. Indeed, there is a precedent in the common law, the case of *Re T*, which involved the withdrawal of consent to medical treatment, where the person withdrew her consent. As a result of a private meeting with her mother it was felt by the court in that case that she had exercised undue influence and the operation went ahead. The withdrawal of consent was deemed to be invalid. I think we have to look at this very closely because when we talk about incapacity, what we are talking about is decision-making, the ability to consent, and the ability to refuse. In law we have three elements to that. We have capacity, yes, that is important; we have the need for information, which is the second ingredient; and the third ingredient of consent is that the decision was freely made. If you put a gun to somebody's head and say "sign this", you do not have consent. Nowhere under the Bill is that kind of issue envisaged. What I identify are three categories. The first category, which in one sense is perhaps the easiest to deal with—do not read too much into that as it is a relative thing—is people with incapacity and we have got a common law at the moment, and indeed the draft Bill seeks to put it on a statutory footing. At the other end of the spectrum we have people who have capacity, who function quite well in society, there are elements of vulnerability maybe through age disability, but on the whole the abuse is minimal, and I hate to have a kind of tariff for abuse, but the abuse is minimal, they are coping and they are probably telling you "Do not do anything, because if you do intervene you destroy the one bit of family life that I have got". The category in the middle is the most difficult one because there you are dealing with people who have high levels of vulnerability, who maybe are totally dependent on an individual for care, and of course are open to undue pressure being placed on them to decide. At the moment they would fall outside the Bill. My argument would be that they should be within the Bill, subject to numerous safeguards. As I say, it is a very difficult piece of legislation to draft because otherwise you say this is not a valid consent they have given because of undue influence, but they have no remedy, whereas if they were just over the line into incapacity the remedy or the protection would be there.

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Mr Burstow: Our task is to make recommendations back to the Department about how the Bill might be changed to reflect those concerns. It would help us discharge that task if after today you could reflect further and offer us some more of your opinions on how you could give effect to what you have just said. You have set out the test of understanding, information and freely made being three elements and it would be useful if that could be translated into something that parliamentary draftsmen would feel more comfortable with.

Q517 Mrs Humble: Following on from Paul's last point, what is the situation now and is this a genuine gap in the law? You said in your last sentence that for such an individual, if they have given their consent freely, or are deemed to have given their consent freely, there would be no remedy. Is that really the case? Is there no remedy under the existing law or is it more that it would be extremely difficult to prove it? I know of a case where one elderly person genuinely changed their mind, they did give consent freely to do whatever, or for the individual to take money off them, and all of a sudden, the next week, they said "Oh, I wish I had never done that" and then challenged it, but they had given consent freely. More often they do not want to get involved in the legal system so we are back to that catch where in order to proceed through the courts you have to have witnesses, you have to have somebody who is willing to come forward to give evidence to prove that they were misled, forced or victimised in some way. Is there actually a genuine gap that expanding the definition in this Bill would fill or would we still be in the position of not being able to prove cases?

Professor Williams: I think that question raises a number of elements and it is perhaps best divided into criminal and civil law. I think what you say is absolutely right, and what Master Lush was saying was absolutely right in respect of the criminal law. In effect, I think what we have done is to decriminalise vulnerable adult abuse because rarely do we prosecute the cases of vulnerable adult abuse. In part that is an evidential problem and the case Master Lush cited is a good example—a person does not have capacity or it would not be in their best interests to give evidence. I cannot believe that is the case in every situation of vulnerable adult abuse, and yet talking to social workers, very rarely are they involved in criminal proceedings. If they worked in child protection they would be. If they are in adult services they are not. We do not use the criminal law. The Youth Justice and Criminal Evidence Act may help because it does provide some assistance for vulnerable witnesses to give evidence: pre-recorded video interviews; interactive video link and so on. That might help and it will be interesting to see what the effect of that particular piece of legislation will be. I think we have to accept that in criminal law you will not be able to prosecute in every case. Indeed, in some cases, as indeed with child abuse, prosecution will not be in the best interests of the person. I think the criminal law has a role to play and we need to raise its profile, which is why I welcome the central involvement of the police in the No Secrets

vulnerable adult protection procedures. It is not a panacea by any means, please do not misunderstand me, but I cannot believe that the low level of criminal prosecutions in any way reflect the level of abuse that goes on of vulnerable adults. If you look to the civil law, the frustration that I come across quite often when talking to social workers is—looking at my middle category of very vulnerable people—"We know they are being abused, it might be physical, financial, emotional, sexual, or all four. We try to persuade them to do something, we try to get in place alternative methods of support, but the person still says no" and social workers will say that on Friday afternoons they have to walk away from that and wonder whether the person will be alive the following day. In law there is nothing that really can be done. We do not have the equivalent of Child Protection Orders, and I am not advocating that we go down the Children Act route, but the social worker is totally without any legal power in that respect. They do not even have a statutory duty to investigate such cases, which is a major gap because the abuser can turn around and say, "What are you doing here? Clear off. I own the house, you are not coming in", and we go back to the kind of Jasmine Beckford type case that we saw in child protection. There is a major gap and it is crying out to be filled by a new public law that recognises that in extreme cases compulsory intervention is going to be necessary, otherwise I think No Secrets is not going to work as it should because it is a constant frustration of social workers and health care professionals that "We cannot do anything and we worry what is going to happen if the person remains in their home". I come back to the positive obligation under the European Convention to protect people from inhuman and degrading treatment, and the question is do we have laws in place that do it? My argument would be that we do not and that is a major gap.

Q518 Mr Burstow: What I am still not clear about from what you have said today, and in your own paper, is how do we get hold of defining "extreme" because the danger is we wind up with a definition that captures an awful lot more than that and, therefore, really does erode the autonomy of the individual. Can you help us a bit further with how we actually capture the definition of "extreme" cases?

Professor Williams: I absolutely agree that is the danger. What I do not want to do is capture the second category I mentioned, people who function well even though they are being subjected to minor abuse. I think, in a sense, it comes down to identifying levels of vulnerability and levels of dependency. Undue influence is very difficult to prove, I think that has always been the case in terms of wills and other documents, but it is not beyond proof. Again, going back to some of the things that Master Lush was saying about burdens of proof, if there is a position of power and influence, maybe if there is a *prima facie* case that this is an abusive relationship and undue influence is being exerted, the burden of proof could be reversed. Yes, again there are human rights issues there that we have to

look at, but it is not necessarily outside of the Human Rights Act to reverse burdens of proof in such cases in performance of our duty of protecting vulnerable people. I am quite happy to think on paper as to how we might go about it. If we look to the American experience it is do-able. There are various definitions. Most of the states have elder abuse protection laws. There are some useful models for defining vulnerability. It is really encapsulating the notion of vulnerability and also the relationship, it is looking at those two features: how vulnerable is this person; how close is this relationship?

Q519 Mrs Browning: I just wanted to ask, following on from that, from what you have just said presumably from the American experience it is not a matter of categorising certain types of disability in any way and the relationship with the key person presumably comes into play there. Unless this is actually put in statute I cannot see how we are ever going to get the resources behind it because as it is a social services' responsibility, we all know that social services departments around the country, because of difficulties of resources, tend to prioritise their statutory responsibilities quite naturally, hence the amount of money that is spent on children's services because of that statutory obligation. Unless that is put into statute, I cannot see that there is going to be any progress in this area at all.

Professor Williams: I think that is absolutely right and I think social services authorities are quite open about that, that they have to cover, as you say, their statutory obligations, which is why I think that a duty to investigate vulnerable adult abuse would be a very important development in terms of implementing No Secrets. On the resources issue, vulnerable adult protection will not be cheap, just as child protection is not cheap, it is going to cost. I do not think anyone has done the costing of this.

Q520 Mrs Browning: I was going to ask you that.

Professor Williams: I am not aware of anyone who has scientifically looked at the cost. One problem is if we do not do anything, what is the cost? Certainly there is a social cost but also I think there is a financial cost because invariably if, say, it is financial abuse, if all their money disappears then the person's ability to look after themselves goes as well and they then become dependent on social services intervention; social services may be paying for residential care and perhaps they will be in receipt of benefits. Similarly, if it is physical abuse it may require hospital resources, so there is a kind of additional cost, as it were, in not having the protection there. We cannot deny that it will cost and that local authority social services departments in the absence of a statutory duty will prioritise and this will not be a priority, despite the immense amount of good work that has been done in local authorities.

Q521 Baroness McIntosh of Hudnall: Professor Williams, can I just take you back a step to the analysis that you were making of what you would need in order to be able to put together something on

the face of the Bill that would call to account those who are engaged in abuse. Would you agree that obviously the vulnerability of the adult in question is key, as you said, and the nature of the relationship?

Professor Williams: Yes.

Baroness McIntosh of Hudnall: But is it not also the case that the definition of "best interests" becomes very critical at that point? We are going to come on to that issue but I wonder when you are thinking about this if you could tie that in because clearly it is possible that when action is taken on someone's behalf, that action might be viewed from one perspective as a form of abuse, but viewed from another is in that person's best interests. I wonder whether your questions about best interests, which you raised in your submission, might be linked back into those issues.

Chairman: If we could have the next question first because it relates to that.

Q522 Baroness Wilkins: There are concerns obviously that "best interests" can be interpreted in too paternalistic a way. You suggest replacing the term "best interests" with "in the interests of promoting the human rights of the person". How do you feel that would enhance the Bill?

Professor Williams: I think "best interests", rather like "welfare of the child", is a term we use and it is quite a useful term in one sense, but it is also a term that on occasions can lead to the suspension of thought and certainly the lack of thought process behind the decisions: "It is in the person's best interests to treat them, and there we are". It is an immensely complex thing to actually try and work out what is in somebody's best interests because there is a best interest in being protected, there is a best interest in having your autonomy protected regardless of what is happening to you. I suppose, to put it quite bluntly, my worry with incorporating or using the best interests test in new legislation is that it will bring with it, if you like, all the baggage that the current common law definition has. What I am keen to see is that under the law local authorities, health authorities and individual professionals do what I would choose to call a human rights calculation in deciding whether intervention is or is not appropriate. Again, yes, autonomy and protection are very, very difficult things to define but we have to take them on board. My fear with the best interests test is that we look very much towards protection, which to some extent goes against what I just argued. It is the full calculation, looking at both sides of the equation and coming to a decision. There are competing interests, of course, in the human rights calculation: the right to a private life versus the right not to be subjected to inhuman and degrading treatment. We cannot generalise about that. We cannot say that protection is always right, that Article 3 is always right and Article 8 is always wrong. My concern is that "best interests" brings with it a history, rather like "welfare of the child", we simply stick the label "yes, best interests, therefore it must be right", and there is not necessarily a real

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thought process behind that decision. Targeting it directly on human rights will cause us to think more broadly.

Q523 Baroness Wilkins: How do you try to ensure that that human rights calculation is made? Do you write it into the Codes of Practice?

Professor Williams: One, I would like to see it on the face of the Bill, a term “having regard to”, and I think that the function of the Code of Practice would be to lay out the competing rights laid down in the Convention and say that basically “these are the things that you must have regard to in reaching your decision, it is a human rights issue”. “Best interests” gives the impression of being very paternalistic, of doing what is best for you: “Don’t worry, dear, we will always act in your best interests”, and it is much more subtle than that.

Q524 Chairman: What would be the effect if the Bill said that the best interests of the person shall be paramount? We had a long discussion on the Children Act on the welfare of the child being paramount. What would be the legal effect of that?

Professor Williams: I am not sure that we have sorted that out under the Children Act yet. If we said it would be paramount then certainly it is the first consideration, the consideration carrying the most weight, but not the exclusive consideration—It is complicated with children in the sense that there are parents involved and parents have rights under Article 8, right to a family life. If you stuck to the term “best interests of the person” in the proposed legislation I do not think you would encounter that. Who else is there that has rights in this respect? It is not like the child/parent relationship, who else is there? Where are the competing holders of rights? It might emphasise it but in practice probably it would not add much to it.

Q525 Stephen Hesford: I am interested by what you say and I have read and reread your paragraph four which deals with this particular point. If you do not mind me saying, what you seem to do is argue yourself out of what you have just been telling us. I want to press you on that because your first sentence is “Placing the best interests test on a statutory basis is welcome and will ensure consistency” and you then go on to say “I am not entirely happy with the best interests test” and then you say “A less concise but more acceptable term is interests promoting the human rights of the person”. It seems to me that there is an internal conflict there.

Professor Williams: Okay. Point one, I welcome the best interests test being in there if the alternative is what we have got at the moment. I think statutory recognition, plus the facts that are going to be taken into account in determining the best interests, has got to be better than the system we have at the moment which is simply relying on this phrase, “best interests”, plus whatever professional guidance, Codes of Practice, maybe available. Given that, I think to make the Bill even better I would much prefer to see “best interests” replaced by this general reference to human rights.

Q526 Stephen Hesford: But if for those who are having to administer the test, and you talk about dissemination of the idea of best interests as an educative process, there is an element of doubt as to whether they will understand their own duties, which is one of the things that is tied up in your concern—

Professor Williams: It is a concern.

Q527 Stephen Hesford: If you have got a less concise definition coming in, will that not make the job even more difficult for that person who will have difficulty understanding what the best interests test is, which you concede implies consistency?

Professor Williams: It certainly implies consistency, and I do concede it looks better than what we have got at present because it is statutorily recognised and it is embellished in the Act. I do not think that a reference to “human rights” would be any more difficult to understand, and in some respects would be easier to understand, because it would set out quite clearly what is the internal debate within the European Convention on Human Rights, namely the struggle between autonomy and protection. In any system we have, if people do not take that on board then I think we are failing vulnerable adults, it has to be part of the equation. My concern is that best interests, even though it is better than what we have or do not have at present, does not really invite people to do that calculation. It suggests it is about a kind of paternalistic, “Don’t you worry, we will do it. We will look after you. Doctor knows best” and all the other things that come along. That is my concern.

Q528 Baroness McIntosh of Hudnall: Just going back to the earlier point, do you believe that best interests, as far as we are able to describe them, actively work against protecting people from abuse? What you seem to be saying is that the best interests test is so loaded in favour of the person making the substitute decision that it could actually act as a mask for decisions which were in fact abusive. Is that what you are saying, because if it is that is rather serious?

Professor Williams: I think I am saying two things. One is we need a system whereby people are protected and at the moment, particularly people in my middle category as it were, people who are extremely vulnerable and require intervention and protection, the emphasis is there, and that in my view would be in their best interests in some cases, but not all. The term “best interests” is worrying because in a sense it is one dimensional, it is about doing what the substitute decision-maker thinks is best for the person, and there are a whole load of assumptions behind that: “This is what I want and what any reasonable 85 year-old would want” and the family say this is what he/she would want and, therefore, it must be in their best interests. What I want to do is put in the second dimension, which is, yes, but doing something, doing nothing, not treating the person, not resuscitating them, removing them from their home maybe, interfering with their autonomy, may also be in their best

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interests. The given formulation of “best interests” has a history that in my mind is based in paternalism. I think we need to focus people’s attention on doing the calculation, as I say my human rights calculation, and looking at the various competing interests rather than saying “Going into the residential care home, going into the nursing home would be nice because it is comfortable, there is a nice, big television, you will be warm” and there we are, even though the person has made it clear that they were born here and want to die here and do not want to go. It is getting people to do that calculation, which in part may be a safeguard against some of the risks that were identified earlier on about overzealous use of the kind of power that I am suggesting. It is down to calculation rather than the assumption that paternalism is always best.

Q529 Huw Irranca-Davies: Could I push you a little bit further on that aspect of the calculation. You referred to it a little bit earlier on as the necessary codification that would underline something that was on the face of the Bill. If the essence of it, if the nub of solving this particular issue, is to do with the codification that lies under what is on the face of the Bill, could that codification not lie underneath “best interests” equally to the human rights?

Professor Williams: I think if one links “best interests” with really what I am trying to suggest in the paragraph, you keep the words but you link it somehow, perhaps in the list of factors to be taken into account, you include it there, that may be an easier way of doing it. As I say, what I am desperately keen to ensure is that we do not say “it was best interests before, we bring all that in with us”, I want people to do the calculation. Yes, you could include it in the section and say “have regard to the person’s human rights”, indeed providing on the face of it, as it were, people will go with that.

The Committee suspended for a division.

Chairman: I fear there may be another division in the Lords very soon. Could we move on to general authority.

Q530 Mrs Humble: Could I ask a very brief supplementary on this issue of a person’s best interests. You have been talking about human rights and one of the other suggestions that has been put to us is that the Bill should define “best interests” as “best personal interests” of the individual. Will that go some way to answering your concerns or would that further muddy the water? The counterweight to personal best interests would be that sometimes an individual’s best interests might be better served in circumstances involving them and their family, or wider issues which could perhaps then not have the priority. Could we just have a brief comment on that?

Professor Williams: To some extent that would muddy the water. It addresses an issue that in applying the best interests test, whose interests are we actually looking after? Of course they are interlinked because the interests of the informal carer are going to be important in looking after the

interests of the cared for person. An immediate reaction to “best personal interests” would be, as you say, to muddy the water; to some extent the worst of all possible worlds.

Q531 Baroness Barker: I have a question sparked by you mentioning the second strand of best interests as you see it, one of the consequences of not making an intervention. Given that and some of the other points you have made that human rights are part of the underlying concerns in the Scottish Bill, do you think that taking “best interests” out and using the format of the Scottish Bill with the principle of best approach would go some way to meet your concerns?

Professor Williams: I think it would go some way to doing it, yes, I do. I think it is an interesting piece of legislation.

Q532 Baroness Fookes: You give a general welcome to the concept of the general authority but you also indicate that there is the risk of abuse. How significant do you think that abuse is likely to be?

Professor Williams: That is very difficult. Master Lush was referring to the difficulties of identifying possible abuse with enduring power of attorney and I think it would be even more difficult with the general authority. I suppose the nearest we have as an analogy is the idea of appointeeship for receipt of benefits. Again, I regret that much of the evidence is anecdotal but talking to quite a number of social workers they do tell me that they know appointeeships are actually being abused, that the money is not being used for the benefit of the person entitled to receive the benefit. I think that is worrying because there is a mechanism under appointeeship for control but, again, the evidence, the anecdotal evidence I regret, no more, appears to be it is not used. To some extent it is rather like putting Herod in charge of a nursery, that sometimes by giving that person general authority or an appointeeship you simply “regularise” the abuse: “I am the appointee, therefore I can buy my new car because I take mother out once a year to visit father’s grave. That justifies me because I am the appointee or I am the person with general authority”.

The Committee suspended for a division.

Q533 Baroness Fookes: You suggest that there should be additional safeguards to protect against abuse in using the general authority. What do you feel they should be on the face of the Bill or in the codes and is there a possibility that this might make it all very cumbersome?

Professor Williams: I think there should be something on the face of the Bill to give it the necessary statutory basis. It is possible that the detail could come in codes. I fully accept the point that this could become bureaucratic, both for those who are called upon to administer but also for the people who are exercising the general authority because the last thing they want is a heavily bureaucratic regime imposed upon them, and there is a cost factor as well. I think it should be minimal but people should be aware that there is the possibility that their

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spending of the money, the decisions that they make, at some stage they may have to be accountable for. That could involve the keeping of very simple pro forma accounts—very simple—what the money has been spent on, or maybe a diary as to why certain decisions were made. It is probably far too expensive to have those checked every year, but the possibility may be of random checks?

Q534 Baroness Fookes: By the local authority, would you envisage?

Professor Williams: The local authority would seem to me to be the key people to do this because invariably they will have access to the person, they will be working with the person who is providing services. Social workers are very well informed about what is going on. They know, I think, when there are problems. They know when possibly financial abuse is going on. In those circumstances perhaps the social worker could initiate some kind of audit. I emphasise very simple records because we do not want to scare off the people who undertake this and the majority of informal carers are wonderful people.

Q535 Baroness Fookes: Would you envisage that, say, a neighbour who was concerned, or somebody else who was concerned, would channel that concern to the local authority?

Professor Williams: Yes, I think that is a possibility that could be done. One might go some way towards protecting anonymity. I think the useful thing about channelling it through the local authority is that the local authority then has the responsibility for initiating action, you do not leave it to the person who is being abused to do so. Again, looking at the American experience of mandatory reporting, relieving the victim of responsibility for “where do we go from here” is a very significant factor in prosecuting vulnerable adult abuse and protecting vulnerable people. Yes, there could be a whistle blowing mechanism for neighbours, concerned friends, concerned relatives, and concerned carers.

Q536 Mrs Browning: I am concerned about social services taking responsibility for this because, by definition, if social services are providing the services then the person concerned has limited assets. The people who have got the assets are the people who are self-funding and they would not come under social services’ remit at all. I would be quite concerned about that route because apart from maybe a property which someone might try to sequester, the people who are self-funding would be the ones who I would have thought would be most vulnerable to having their assets removed under circumstances that might not be proper.

Professor Williams: I have a two-fold response. One, if you look at people who may be within the social services’ net, taking £5 a week off them is probably going to be as significant as taking £100 or £200 off someone who is outside of the social services system, so it is a relative calculation. I entirely take the point

that it is difficult to identify those who are not in touch with social services and I do not know how you would do it, I really do not.

Q537 Mrs Browning: But surely if someone has applied for power of attorney there is a record of who has applied and where they are. They may not even live close by.

Professor Williams: Yes, under power of attorney you are into a formal process. Similarly with appointeeships, at least we know who are appointees because there is a process. I am conscious all along of throwing babies out with bathwater but if people are wanting to use or take advantage of the general authority, somewhere maybe that should be logged in in order to give them the legal protection, so there could be a very simple logging in with a local authority, who I think would still be the ideal people, but at least we would know that somebody is exercising the general authority. I entirely take the point that we are perhaps in danger of formalising something that is supposed to be essentially informal and that in the majority of cases works quite well, but given the cases that do go wrong I think we do need some formal, albeit light touch, registration process of simply logging in, “I am exercising a general authority”, “Here is the sheet of paper which tells you what your duties are and there is the possibility of a random check”.

Q538 Chairman: Is it not the case that even if somebody is self-funding but under a protection order in a private residential home, because they have been placed under a protection order by a psychiatrist then the social workers do know about it and they are in touch and have a degree of power over the health and welfare of that person?

Professor Williams: I think in that situation, yes, because there is a professional involvement and maybe a health involvement, but interdisciplinary working, the No Secrets procedure, should ensure that these things are fed in. I guess it is the person who is outside of all this, who is reasonably comfortably off and is not within the social services or the health care system—what happens to them? They are managing but there are problems.

Q539 Mr Burstow: I want to pick up on a couple of points. The first is to reflect back to you that there is an expectation here in what you are saying that there is a wider acceptance in society about the existence of older and adult abuse and certainly I am aware of a taboo existing, it does not really come out in the same way it has with child abuse. Particularly I wanted to explore this issue of a general authority and your proposition of a human rights calculation and whether or not you feel that such a calculation is an onerous burden to be placed upon a carer and, therefore, it should not be placed on the general authority but more appropriately placed in more formal substitute decision-making arrangements dealt with elsewhere in the Bill.

Professor Williams: I think in terms of public awareness of vulnerable adult abuse, the public are unaware, there is absolutely no doubt about that, it

does not happen, but it does. If you talk to social workers, talk to health care practitioners, they will tell you it does happen and it happens quite frequently. Precisely what the incidence is we do not know, but it happens. Yes, I think the human rights calculation can be a complex one, although to some extent that is dictated by the particular decision that you are making: is it a decision relating to a significant investment or a major piece of health care where there are serious risks, in which case the calculation may be quite complex. I think that for the routine day-to-day kind of decisions that we are looking at under the general authority the calculation is relatively simple and it comes back to having codes that are aimed at specific groups of individuals, so for people with general authority their code would be, in very general terms, trying to explain how the calculation works. As I say, we do need to be very careful that we do not frighten people off because if all these people walk away from it then we have a major problem. One has to be careful. I think it is do-able. There is some stuff in the Lord Chancellor's Department's draft codes that could usefully be used in new codes in terms of trying to explain to people what is involved in decision-making for other people, what their duties are. If it is an immensely complex decision then, yes, I think the human rights calculation itself is much more complex.

Chairman: If we can move on to lasting powers of attorney.

Q540 Huw Irranca-Davies: In respect of, first of all, protecting older adults from abuse but also detecting cases of abuse where they are happening, what are your thoughts in respect of a formal regular system of inspection of people who are vested either with lasting powers of attorney or, alternatively, with a general authority? Would a formal regular method of inspection be a valid one, an appropriate one? Is it overkill, in effect? Is it practical?

Professor Williams: I think the general authority would be very much as I have just described, a light touch—it would need to be logged in. For the lasting authority, I think it is a pretty significant decision to say that “in the event of my being incapacitated I give you responsibility for my financial affairs”. I think people may be reluctant to do that unless they know there are adequate safeguards in the system. I think that does presuppose that there is some kind of inspection process in place. Again, we come back to resources, we come back to bureaucratising the whole process, although I think someone who accepts lasting power of attorney, or enduring power under the existing law, accepts a greater responsibility and a recognition that it is going to be more time-consuming, you are going to need to go through the formalities. Under the lasting power of attorney I would like to see a greater level of accountability than maybe we see under the enduring powers of attorney.

Q541 Huw Irranca-Davies: And you would want that laid out on the face of the Bill?

Professor Williams: I would want the principle laid out on the face of the Bill, the detail elsewhere. I do not know whether it is a good example to say rather like one audits direct payments. I am not sure that is a good analogy. If I sign a document saying “You look after my financial affairs in the event of X”, I think people are entitled to safeguards. An increasingly worrying group of people is people who appear to sign an enduring power of attorney and yet you know full well that at the time of signing they lacked capacity, their hand was guided over the bottom of the paper basically.

Q542 Huw Irranca-Davies: On that basis, as the Bill is currently formed we have under section 12(2): “P may, at any time when he has capacity to do so, revoke the power.” On the basis of what we are talking about, which is a formal regular system of inspecting individuals who are given that lasting power of attorney, should it not also work the other way recognising that the capacity of an individual who gives that power to a donor is function specific, is time specific, will fluctuate over various periods and various instances? Should there be something within the Bill that recognises we should go back to that individual on a periodic basis?

Professor Williams: I think, again, that is extremely useful because incapacity is not necessarily once and for all. Particularly important is the point you make that incapacity is not a general thing but is function specific. Again, coming back to this human rights point, one does need to periodically review whether continuation of this power of attorney is appropriate or appropriate in its current form because maybe things have improved and maybe it has just become so comfortable that no-one is going to challenge it. I think that could quite usefully be part of the process, especially where the prognosis is that the person may actually improve, perhaps less so where you are convinced that the person's capacity will not improve, it will get worse, but where there is a possibility that with education, training or whatever, the person may improve then I think that would be helpful.

Chairman: Thank you very much. Can we conclude now with advance decisions to refuse treatment.

Q543 Lord Rix: In your written memorandum it was suggested that advance decisions should be time limited, needing to be updated, say every five years, while the person still had capacity. You then went on to say, alternatively, an incentive to update could give doctors more scope to deem advance decisions less applicable after a fixed period. In your view, how could a requirement be imposed on individuals to review advance decisions, whilst they are still capable, to ensure that the request remains current? How would you give power to the doctors, which might be an unpopular move with many, to make alternative arrangements to these advance decisions to refuse treatment?

Professor Williams: Firstly, I very much welcome the inclusion of advance decisions in the Bill, I think that is a very positive step. I am concerned that, perhaps as envisaged in the Bill, the advance

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decision does not have a shelf life. I might make a decision today that in the event of X, do not do Y, because Y is horrendous and the possibility of full recovery is zero, so I say "If I am incapable, do not do Y, let me die". Five years down the line, Y may be a relatively simple unobtrusive form of treatment and I think one has to ethically say should that be allowed to stand because the person made it in one context, that context has now changed. The context was that it was intrusive, likely to be unsuccessful, and that has now changed. I think that people should be encouraged, and perhaps I would go even further and say required, to revisit their advance decision periodically. That is one way—to say that advance decisions have a shelf life of five years after which you come back and renew. The alternative is a suggestion I floated in my submission that perhaps the doctor's interpretation after five years, or a period of time, could be slightly more liberal and you would give the doctor greater scope to say that circumstances have changed and, therefore, the advance directive should not stand.

Q544 Lord Rix: You would not think that this negates the whole purpose of an advance decision?

Professor Williams: It might run the risk, but at the same time I think we need almost a kind of public education campaign as to what advance decision making is all about. It is looking in the year 2003 and saying "In the event of this, do not do that", and it is based on all that is happening in 2003, but in 2006 it may be desperately different. I somehow think that people should be expected to revisit advance decisions because otherwise you perhaps impose on the medical profession very difficult decisions.

Q545 Mr Burstow: In 2006 only three years has gone by and you were talking about five years.

Professor Williams: I am pulling figures out of the air. I mentioned five but it could change overnight, of course. To some extent we have just got to pick a figure and go with it that is reasonable in the sense of the rate of development of medicine. Five may be inappropriate, I do not know. I think the principle is that the expectation should be that we come back, revisit and think "Do we want this to continue", because otherwise it may involve the medical profession in quite complex ethical questions: "They said do not do Y, because then Y was terrible, but actually it is easy-peasy, we can do it".

Q546 Mr Burstow: If Codes of Practice laid down the form that an advance decision to refuse treatment would take, which will be clearly liberal in its interpretation as far as the medical profession is concerned, and also the view of the fact that advance decisions are made absolutely voluntarily, nobody is going to force you to do this, would you not accept then that if they are carefully written, they are not demanding euthanasia or anything of that sort, and give the doctors sufficient scope to review the situation clinically over time, would you not consider that sufficient? The fact that they are made

voluntarily, would you not consider that they should be able to continue to hold good and doctors should interpret them in the best way possible?

Professor Williams: I think that presupposes that the advance decision will be clear and will be—

Q547 Mr Burstow: I am saying it should be on the Codes of Practice so that people know exactly how it should be written.

Professor Williams: It should be on the Codes of Practice, although in a sense I think one has to legislate for those that are not clear and, as I say, would provide the doctor with perhaps quite a serious ethical dilemma at the end of a particular period of time. I think in principle it is desirable that we go back and revisit these decisions that we make in advance because our views may have changed. It is rather like changing your will, you might have fallen out with the person you have left all your money to but you never get round to going to the solicitors to change your will because you have done it, that is it, it is in the bag and you do not want to think about death any more. I think that as responsible citizens we should be encouraged to go back and revisit, whether it be three, five, ten years, I do not know, that is a figure plucked from the air. I think it is an act of responsible citizenship, if you like.

Q548 Stephen Hesford: Just on this point, would not the additional difficulty be that if you had a period of time when there was a statutory duty to revisit and you had a period of five years, on your scheme if there was a decision to be made and it was four years and 364 days a decision would be made under the advance directive but given full force because it is within the five years, but under the scheme Lord Rix was talking about, and doctors have been talking to us about, if the Codes of Practice were sufficiently well thought out there would be flexibility to come in and apply what should be applied at the time, whereas your scheme would actually prevent that flexibility taking place?

Professor Williams: I take the point that any time limit is arbitrary, the age of consent at 16 is entirely arbitrary and a matter of seconds can change things dramatically, but I still come back to my basic point that we have a responsibility to revisit such advance decisions on a fairly regular basis because we are asking professionals to do or not to do things to us in the event of a context that may not exist at the time the decision has to be made.

Q549 Stephen Hesford: You are asking somebody to revisit their advance directive by a certain date which means that they have got to go all through the process of having it witnessed again, rewritten again, or could they merely add a codicil, as it were?

Professor Williams: You could have a short, fast-track revalidation system if you wanted, and I think that might make sense. As I say, it is important that we do go back and look again and say, "Is this really what we want" because when the time comes it is too late.

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Q550 Chairman: Just on a point of principle, as you know the draft Bill puts into statute the current and common law position but supposing those provisions were not in the Bill, what would the effect be, to stay with the common law as it is now?

Professor Williams: We would stay with the common law.

Q551 Chairman: Would that be worse than the position now?

Professor Williams: This is such a sensitive area that I think, insofar as legislation can provide clarity, we need the clarity of legislation rather than common law. That takes us back to the first discussion we had, that common law is okay but increasingly this is becoming an important issue for people.

Q552 Chairman: On the other point about the changing knowledge of medical treatment, if an advance directive said something like “Based on the treatments known to me at this time I wish to refuse treatment”, it would then mean that if treatments changed the directive would not be based on those new treatments.

Professor Williams: Yes, and you would tie it into day one, as it were, the day you signed it. That is possible, although who knows what the person knew on that particular day. That may be a practical problem, an evidential problem.

Chairman: If I can thank you on behalf of the Committee for being so patient and waiting for a long time but we were interrupted by divisions which are outside our control. You have been extremely helpful. If there are any further points you would like to make we would be happy to receive them in writing. Thank you very much.

27. Supplementary memorandum from Professor John Williams, Department of Law, University of Wales, Aberystwyth (MIB 1210)

1. In paragraph 3 of my original submission to the Committee I proposed that the scope of the draft bill should be extended to cover inability to make a free decision as a result of undue influence.³ I had in mind situations where a person has legal capacity but, as a consequence of extreme vulnerability, is susceptible to undue influence by somebody in a position to exert an unacceptable level of influence and thus destroy the notion of a free consent. During my oral evidence concern was quite properly raised about the possible misuse of any statutory power permitting compulsory intervention in such cases. Unless there are safeguards, the right to a private life will be threatened by over zealous use of the power to intervene. Drafting such a clause is immensely complex.

2. Undue influence is not a new concept. The 1993 case of *Re T* illustrates the potential use for it in matters covered by the Bill. It concerned the effectiveness of a refusal to undergo medical treatment which, it was argued, was invalid because of the undue influence imposed on the patient by her mother. The Court of Appeal held that the refusal was invalid. It made a number of observations on undue influence in the context of medical treatment Butler Sloss LJ refers to the nature of consent as follows:

“Although the issues of capacity and genuine consent or rejection are separate, in reality they may well overlap, so that a patient in a weakened condition may be unduly influenced in circumstances in which if he had been fit, he would have resisted the influence sought to be exercised over him. The patient may make a decision which is limited in scope, and there may also be the situation where no decision is made and in those circumstances the principle of necessity will apply . . .”

This demonstrates that the requirement for a freely given consent goes alongside the need for capacity in determining whether an effective consent/refusal has been given. The inclusion of undue influence would, it is suggested, be consistent with what the Bill is seeking to achieve—that is, protection for those who are unable to make decisions for themselves. It is interesting that she regards a decision taken without genuine consent as invoking the principle of necessity (as per *Re F* 1990) and with it the use of “best interests”.

3. If it is accepted in principle that the Bill should include reference to undue influence, it is necessary to define its scope. Lord Donaldson identified two aspects when considering the effect of outside influences:

“First, the strength of the will of the patient. One who is very tired, in pain or depressed will be much less able to resist having his will overborne than one who is rested, free from pain and cheerful. Second, the relationship of the ‘persuader’ to the patient may be of crucial importance. The influence of parents on their children or of one spouse on the other can be, but is by no means necessarily, much stronger than would be the case in other relationships. Persuasion based upon religious belief can also be much more compelling and the fact that arguments based upon religious beliefs are being deployed by someone in a very close relationship with the patient will give them added force and should alert the doctors to the possibility—no more—that the patient’s capacity or will to decide has been overborne. In other words the patient may not mean what he says.”

³ The term “undue influence” is used in this response. However, it is possible that another term could be used such as “unacceptable pressure” if it was felt necessary to distant the concept from existing commercial law and contract law cases.

4. The strength of the will of the patient does, as Lord Donaldson suggests, depend upon the person's vulnerability and the context within which the decision making process takes place. In clause 1 of the Draft Bill attached to the *Consultation Paper on Vulnerable Adults* (Scottish Executive, 2001)⁴ the term "vulnerable adult" is defined as follows (excluding the words in square brackets—see below):

"This Act applies to vulnerable adults, that is to say to adults who for the time being are both:

- (a) unable to safeguard their own welfare, [personal safety] property or financial affairs [and as a consequence are at risk of significant harm]; and
- (b) in one or more of the following categories—
 - (i) persons in need of care and attention by reason either of infirmity or of the effects of ageing;
 - (ii) persons suffering from illness or mental disorder; and
 - (iii) persons substantially handicapped by disability.”⁵

This is a possible model for the proposed bill for England and Wales. The words within the square brackets are not in the Scottish draft; however, I suggest that their inclusion would help to avoid the risks of an over intrusive law that disregards personal autonomy.

5. With regard to the context in which the decision is made (the second factor identified by Lord Donaldson), it is necessary to explore the relationship between the vulnerable adult and the person alleged to be unduly influencing him or her. Under existing law lifetime gifts made within a particular relationship (not by a will) may be presumed to have been made under undue influence. These include gifts by patients to doctors, by clients to solicitors, to religious advisers by recipients of the advice, and by children to their parents. This is something that could be developed if the Bill included reference to undue influence; there could be a rebuttable presumption of undue influence when the relationship is such that the validity of a vulnerable person's consent/refusal should be questioned (for example, professional, carer, family, spouse, partner). If the presumption was not rebutted then the provisions of the Bill would be engaged. Decisions could be made in the same way as for a vulnerable adult without capacity, with the safeguards of the best interest test (or as I would prefer, the human rights calculation). Clearly it would be possible to prove undue influence by persons other than those in a special relationship; however, the person alleging it would not have the benefit of the presumption.

There is much sensitivity around the presumption of undue influence, not least by caring members of the family who may feel affronted by the idea that their input into decision making might be presumed to be tainted. This needs to be addressed in Codes and in the information leaflets. The point is, it is in the interests of the vulnerable adult that they have this protection.

6. Another aspect of the context within which the decision is to be taken is the behaviour of the person seeking to influence the vulnerable person. The influence must be "undue"; persuasion in itself does not vitiate the consent/refusal. Good professional practice in advising a vulnerable adult of the benefits of residential care over community care would easily rebut the presumption. Advice given to a vulnerable adult by a son or daughter that he or she should sign over all their property to them would be less easily rebutted, especially in the absence of independent legal advice.

7. Returning to the draft Scottish Bill, the proposal there is that before intervention in the life of a vulnerable adult is permissible, his or her consent should be obtained,

"... except that his refusal may be disregarded by a court or other person to whom it falls to authorise or effect such intervention if it is reasonable to believe that it is a refusal wholly or mainly consequent upon—

- (a) his being mentally disordered; or
- (b) his having been pressurised by some other person.” (clause 2(1)).

Again, this may be a template for use in England and Wales, although it is less helpful than the definition of vulnerable adult.

8. To summarise, a clause seeking to widen the remit of the Bill to include some vulnerable adults with capacity would need to address the following:

- (a) Vulnerability—the Scottish Draft Bill is of assistance.
- (b) Normally the autonomy of the vulnerable adult would be respected, even though the decision may be irrational or not in his or her best interests. However, in cases of high levels of vulnerability plus the risk of *significant* harm, compulsory intervention should be possible.
- (c) If so, the Bill would need to address the context within which the decision is being made.

⁴ The Bill was drafted by the Scottish Law Commission in its *Report on Vulnerable Adults* (Scot Law Com No 158).

⁵ Note that the Scottish Executive in its paper identified four distinct groups and, on the grounds of equity, argued that there is a case for extending the protection of the law beyond the vulnerable with mental disorder. The four categories are (i) mentally disordered, vulnerable and incapable by reason of mental disorder; (ii) mentally disordered, vulnerable and not incapable; (iii) not mentally disordered but vulnerable and incapable because of inability to communicate due to physical disability, and (iv) not mentally disordered and not incapable but vulnerable because of age, infirmity, illness or physical disability. (See para 18).

- (i) The relationship between the “decision maker” and the “persuader”. Here there is the possibility of including a rebuttable presumption of undue influence in certain relationship. I would emphasise that the presumption would be extremely useful, although it is not an essential component of extending the law to a wider group of vulnerable people.
 - (ii) The use of legitimate persuasion should not be deemed to be undue influence.
 - (d) Any decision to intervene, and the nature of that intervention, must satisfy the test of proportionality.
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Wednesday 15 October 2003

Members present:

Barker, B.
Carter, L. (Chairman)
Fookes, B.
Knight of Collingtree, B.
McIntosh of Hudnall, B.
Rix, L.
Wilkins, B.

Mr John Bercow
Mrs Angela Browning
Jim Dowd
Mrs Joan Humble
Stephen Hesford
Huw Irranca-Davies
Laura Moffatt

28. Memorandum from the Law Society (MIB 1030)

Below is a summary of our concerns. However we wish to stress at the outset that we welcome publication of a draft Bill and look forward to a Bill being introduced to Parliament in the near future.

SUMMARY OF CONCERNS:

1. *Best Interests*

We consider the Scottish “general principles” are more appropriate and less paternalistic and prescriptive. The Bill should make the intention of the legislation more clear ie, that it is not intended to interfere with a person’s own decision making where they are able to do this. The Bill needs to show that it intends to encourage supported decision-making and regulate substitute decision-making where this is appropriate.

2. *Public Law duty to investigate suspected abuse and exploitation*

We consider the Bill has missed an opportunity to provide adequate safeguards for the physical (and financial) safety of vulnerable adults and that Social Services and appropriate NHS bodies should be vested with similar powers and duties as those contained in the Children Act 1989.

3. *Problems with General Authority*

We welcome this practical provision but take the view that the proposals do not provide sufficient safeguards for carers or individuals. Nor are the powers under a general authority sufficiently defined.

4. *Problems with Lasting Powers of Attorney*

The Law Society have identified several technical difficulties with the Bill.

5. *Alternative Dispute Resolution and the Code of Practice*

These topics are pervasive and are raised throughout the submissions.

6. *Reasonable Belief*

We consider that the test of reasonableness of a person’s belief about a person with impaired capacity should be an objective one.

7. *Assessment of capacity*

The BMA/Law Society guidance may be incorporated into a code of practice, and that any assessment procedure should avoid bureaucracy and over medicalisation.

8. *High Court Powers*

The Law Society considers the new Court of Protection should have its powers specified to increase access to justice for those unable to pay legal advice.

9. *Legal Advice and Assistance*

The objectives of this Bill will be wholly undermined without adequate public funding.

10. *Human Rights compatibility*

Several potential conflicts are identified.

11. *Interface with Mental Health Legislation*

Several overlaps are identified along with suggested ways of dealing with it.

12. *Mutual Recognition of other jurisdictions*

This needs to be specified in the Bill.

13. *Fees*

Consultation group should be wider.

14. *Miscellaneous*

The Law Society of England and Wales has worked in co-operation with Making Decisions Alliance and approximately 15 organisations/individuals on the proposals contained in the Draft Incapacity Bill. These submissions have been prepared having regard to this work and the expertise of the specialist committees and working parties of the Law Society. This submission is also made on behalf of United Response, British Association of Psychologists, Mencap and Royal College of Nursing.

The Law Society welcomes the publication of this Draft Bill. However, whilst we would wish to fully embrace these proposals it is not possible to understand their actual impact without first examining the code of practice which is to accompany the legislation. Much of the detail on which we comment may be intended to be included in this code. In any event, we take this opportunity to raise some specific concerns which we consider would benefit from closer examination.

1. *Best Interests*

1.1 Any act or decision made must be done in the best interests of the person. The best interests principle is extremely important in the implementation of the Act. It should focus the mind of whoever is making a decision on what is in the best interests of that particular person. However, it is imperative that the person's own decision making ability (and/or communicating it) is facilitated first. We are concerned that this should be emphasised in the text so that the best interests principle should only become relevant once it is established that a substitute decision is required. In other words a person should be free to take a risk, make a capricious or a bad decision or one that does not appear to be in their best interests so long as their capacity is not disproportionately impaired and that the decision was an informed one and free from undue influence.

1.2 The Bill does not in our view clearly distinguish between persons who acquire mental impairment from those whose impairment has always been present (for example those who have learning disabilities). The needs of these groups are different. A person with a severe learning disability may have capacity to make some decisions and should be encouraged to do so. The best interests principle is not applicable here, nor for that matter is the Bill save that it should emphasise the presumption of capacity and the requirement to facilitate a person's own decision making. Decisions could be best facilitated and supported by the use of non-legal advocates.

1.3 The factors taken into account will be different where a person has never been able to express a preference and where a paternalistic approach is to some extent unavoidable. Nevertheless an advocate may assist in gaining some insight into the persons own wishes and feelings. However, an adult who acquires a brain injury or develops a disease which impairs their mental capacity may nonetheless appoint a decision-maker (or make advanced decisions). Here the Bill needs to regulate substitute decisions and decision makers. In some respects these characteristics do not sit well together. This, in our view, has caused some misunderstanding that the Bill intends to impose or restrict a person's own ability to make decisions. A clear demarcation of the objectives of the Bill may assist in a better overall understanding of the legislative intent.

1.4 The listed factors to be taken into consideration in best interests decisions are not identical to those contained in the 1995 Law Commission recommendations. In our view regard to cultural diversity should be explicit. The Adults with Incapacity (Scotland) Act 2000 has a less passive/paternalistic concept of "General Principles" that has been very successful. Careful thought needs to be given to this issue as it goes to the root of the legislation and how it will be applied to individual cases. It may be a case of finding the delicate balance between semantics and legislative intent.

1.5 In Scotland the power of attorney only remains in force for as long as it is required. There is no formal de-registering process. By applying the general principles to a person whose capacity fluctuates, the power is invalid during lucid intervals. The general principles being more person centred as opposed to having “best interests” imposed means that it would be wrong in principle to impose the will of an attorney where the donor has capacity no matter how much he purports to be acting in his “best interests”.

1.6 Care must be taken to ensure fluctuating capacity is acknowledged and not held back through bureaucracy. However, it needs to be manageable for others if capacity fluctuates from hour to hour, to protect third parties such as banks and contractors.

1.7 In terms of ethics, the Scottish General Principles are preferred to the Best Interests proposed. They are now tried and tested whereas “Best Interests” departs from other jurisdictions notably US and Canada. If the general principles are not adopted we would suggest incorporating para 1(2) of the Scottish General Principles into England and Wales law.

1.8 Finally, given the weight this clause has on the application of Bill, we consider it should be placed as Clause 1 (along with the “presumption of capacity”) to indicate the importance of the principle throughout the Bill.

1.9 The code of practice should draw heavily—and explicitly—on the guidance given by the President of the Family Division, on the assessment, meaning and implications of competency and capacity, notably in *Re MB* 1997 2 FLR 426 (1997) 2 FLR 426; [1997] FCR 541; [1998] 38 BMLR 175 and *B v An NHS Hospital Trust* 2002 [2002] 1 FLR 1090; [2002] 2 All ER 449; [2002] 65 BMLR 149. It would also be important to include practical case examples, following the format of the guidance accompanying the Disability Discrimination Act 1995.

2. Public Law duty to investigate and protect in cases of suspected abuse or neglect

2.1 Children have long been protected by a public law duty enabling the NSPCC or a Local Authority to investigate, and take steps to protect a child from suspected abuse. The Law Society takes the view that it is time for vulnerable adults to have similar protection. This was recommended by the Law Commission. The absence of this in the Draft Bill fails to reflect widespread public support for the recommendations. Abuse, neglect or exploitation of learning disabled and elderly persons often goes unnoticed by the general public and the experience itself is often silencing for the individual. There needs to be a safe forum created where abuse, exploitation and neglect can be disclosed and addressed in the most appropriate manner using a multi-agency approach. We propose that social services and an appropriate NHS body should have investigative powers and duties which could be triggered through a code of practice to refer suspected cases which come to the attention of GP's, Social Workers or any concerned person. The court will be empowered to call for reports (Clause 39). It is suggested that there be corresponding Section 7(1) Local Authority Social Services Act 1970 guidance issued by Minister of State and Welsh Assembly to ensure compliance. The Draft Bill proposes a continuation of Lord Chancellor's Visitors (LCV's), however they lack the powers, resources, status and expertise of a Local or Health Authority. Also, LCV's are too restricted (Clause 49). They should include psychologists and neuro-psychologists etc.

2.2 Whilst exploitation may include financial abuse, it is difficult to monitor as there is rarely any manifestation to alert a concerned person. Nonetheless a duty to keep written records could be imposed subject to a de minimus rule of an estate under £5,000. In these circumstances the court should however be empowered to order that records be kept of a smaller estate, if it thinks fit.

2.3 Despite the retention of a criminal offence of “ill treatment and neglect” (currently at s127 Mental Health Act 1983) the new provision does not include “exploitation”. This should be included to apply to financial exploitation. However there are the incumbent problems of the criminal standard of proof. The offences do not address the wider issues of protecting the victim during investigation and providing a place of safety etc, or the threat of consequences resulting from disclosure to the police which may prevent vulnerable witnesses from coming forward.

2.4 Whilst the Court of Protection are to have power to call for reports, there is no corresponding duty for the reporting bodies to alert the Court that a need for investigation exists. It is a “function” of the Public Guardianship Office to “supervise” the exercise of donees' powers but there is no over-riding duty.

2.5 The Law Society argues for a range of parallel civil and public law remedies (not dissimilar to those provided by the Children Act 1989) to effectively protect this vulnerable group. It may be possible to effect this by rewording the Bill (and by adding “duties”) and draw together all the powers under one heading. Presently the powers are dispersed throughout the Bill. This is confusing and fails to prioritise this important issue.

2.6 The success of the Scottish Act is due in no small part on the duties imposed on local authorities. In addition there was created a “Mental Welfare Commission” which has oversight of both the PGO and the Local Authority. These practical safeguards are a desirable feature which should be incorporated into England and Wales legislation. This should also prevent a two-tier system for the protection of vulnerable adults being created in the UK.

3. *Problems with the General Authority*

3.1 The Law Society welcomes this provision but with some caution. On the one hand it is a practical solution to the day-to-day authority to make decisions. However, the Bill provides insufficient safeguards. The general authority requires a counter balance of corresponding responsibilities and safeguards. There is anecdotal evidence that under existing financial powers, abuse runs at approximately 20% of cases. Where there are no formalities it is difficult to monitor the prevalence of abuse. The general authority applies in hospitals, care homes, day centres, private homes and any public place or setting where services are provided. The scope for misuse of these powers is therefore great.

3.2 Overall there appears to be a lack of guidance on the use of these powers. For example, there is no definition of "care". It is those who are providing "care" who make best interests decisions on behalf of others without checks. Where is the line to be drawn? The nature of the functions of care and the nature of the relationship needs to be clarified to protect P and the "good Samaritan" who comes to P's aid in good faith. This will need careful examination and the practical implications explored. People will be empowered to make decisions until such time they are challenged and so safeguards and parameters do need to be set which are clearly identifiable. As a minimum, it is suggested that any decision which is likely to have a substantial impact on P is not one which should be made under a general authority eg change of carer.

3.3 The Bill should emphasise that if the general authority were to be used to consent eg, to medical treatment this may not be lawful. Prescribing is a medical decision subject to professional guidance. The general authority may, however, be used to administer the prescription and to place a requirement on the service provider to consult the carer. It is of course open to an individual to *nominate* a donee to consent on their behalf or make an advance statement should they wish to do so.

3.4 There also needs to be an informal or alternative disputes resolution mechanism. This would be of assistance to carers where a dispute does not satisfy the tests for eligibility for legal aid, or where an informal consideration is proportionate to the problem in question. An example of ADR could be the extension of the patient liaison advocacy services in relation to medical treatment disputes, this would prevent the Court of Protection being called upon for all matters where there is misunderstanding and/or a low risk outcome. Dispute resolution other than Court of Protection would also assist attorneys and service providers.

3.5 No other jurisdiction (as far as is known) has a General Authority as part of their substituted decision-making law. The Law Society would therefore suggest proceeding with caution so as to find the correct balance between efficacy and safeguards. The scope of a general authority in particular needs to be clearly defined on the face of the Bill. This is because it would not be realistic to expect informal carers to have regard to a code of practice.

3.6 The Law Society is of the view in any event that Clause 62 (a) pledge credit etc be removed and the test for reasonableness be an objective one. (See "reasonable belief").

4. *Problems with LPAs*

4.1 It is not clear why more than one attorney has to be appointed only jointly or jointly and severally. Some donors would appreciate the option of appointing three or more attorneys on the basis that any two could act. They may wish to allow attorneys to act severally in relation to financial matters, but jointly in relation to health matters, or vice versa. Our understanding is that different donees can be appointed to take different decisions. This is a desirable feature so long as disputes are easily resolved. Otherwise the position of third parties such as care homes may be uncertain if P has been placed in care but the financial donee does not agree to the placement. This should not necessarily prevent an attorney acting severally. The Law Society would also want clarification on whether parts of an LPA can be severed or subject to conditions by order of the court.

4.2 The Law Society recommend that any partial revocation (Schedule 1, Part 4, Clause 16) be effected by an endorsement on the instrument rather than an attachment which may become dislodged.

4.3 On registration, the Law Society take the view that extreme caution should be taken where there are no named persons for notification. The court must ensure that the document has been registered with the donor's free-will. An application for registration without persons named for notification should be witnessed in the presence of the person who certifies capacity and two other persons.

5. *Alternative Dispute Resolution and the Code of Practice*

5.1 These topics are pervasive and are raised throughout the submissions.

6. *"Reasonable belief"*

6.1 Throughout the Bill reference is made to a decision maker's reasonable belief, for example Clause 6(1)a. The Law Society takes the view that this is too subjective and that the phrase should be altered throughout to read "the person reasonably believes and *it is objectively reasonable to hold this view*". This should help avoid arbitrary decisions being made.

7. *Assessment of Capacity*

7.1 The BMA and the Law Society have already published guidance on the functional assessment of capacity. Care needs to be taken to ensure the certification procedure is not too bureaucratic. The assessment of capacity is not necessarily a question exclusively for Registered Medical Practitioners but one which can at times be assessed by other suitably qualified professionals such as psychologists or specialist nurses. The practical aspects of formal assessment could be contained in code of practice but the detail such as who can assess should be stated in the Bill with a “sweeping up” clause so that the Secretary of State can appoint assessors (to allow for emerging expertise).

8. *High Court Powers and the new Court of Protection*

8.1 Modern legislation should be accessible and therefore any powers which are granted to the Court of Protection (Clause 37(1)) need to be specified. If not in the main body of the legislation then by reference to a schedule.

8.2 Further, for this legislation to be effective there needs to be practical consideration given to the resources available to the new Court of Protection. This includes the recruitment and training of suitably qualified judges.

9. *Legal Advice and Assistance*

9.1 The implications to the Legal Aid budget are not discussed in the Draft Bill or explanatory notes. In Scotland anyone who brings an application on behalf of an incapacitated person will have a right to advice and assistance or to representation costs as if they are the subject themselves. If the person without capacity is eligible then so too will their representative, irrespective of their personal means. This is how legal aid applied in UK to litigation friends and we would suggest this would be a suitable model to adopt. It is worth noting that Scottish practitioners lament the loss of ABWOR in these type of proceedings and are currently experiencing delays on applications for legal aid.

9.2 The stated objectives of this Bill will be greatly undermined by the lack of availability of public funding. The need for advance planning for the budget implications is brought to Parliament’s attention so that proper planning can take place and an appropriate enhancement to the legal aid budget identified.

10. *Human Rights compatibility*

10.1 Compatibility has been certified but we are of the view that there is a question as to whether best interests decisions especially those made under a general authority could conflict with human rights legislation. Obviously an advance refusal of life sustaining treatment may put the state in breach of Article 2. Also, the wide application of the general authority may, in the Society’s view give rise to claims under Article 8. Any application to dispense with notification on registration may prevent objections being validly raised which could offend Article 6 as could the lack of appeal procedures on the appointment of a deputy. Similarly Clause 20 should have prefix of “unless the court orders otherwise” before the deputies’ powers are restricted.

11. *Interface with Mental Health Legislation*

11.1 The general authority has a few restrictions (Clause 7) eg not to restrict P’s liberty of movements. However a donee or a deputy can do “any act reasonably believed to be necessary to prevent a serious deterioration in P’s condition”. This may involve loss of liberty in the case of a “wandering” person. It would be preferable for this clause to have greater safeguards in the primary legislation. For example a requirement that where the detention of a person is necessary for their safety that this is part of an overall care plan agreed by health and social work professionals. This is so that arbitrary or convenient “locking away” is avoided.

11.2 As the Bill currently stands there is scope for applying invasive treatment to a compliant person (therefore in the case of mental health, there is no need for compulsion under Mental Health Act). For example, ECT (electro-convulsive therapy) which may be deemed in the patient’s best interest by some but not others, could be applied which could have serious side effects. An example of a better safeguard would be the requirement of a second opinion in circumstances other than for non-invasive prescribing or treatment. Although invasive treatment is available in a non-clinical setting, good practice means this should take place in a hospital where a second opinion should not be difficult to obtain.

11.3 Another area of overlap with Mental Health legislation is the nearest relative/nominated person. Under the Mental Health Act they have powers to apply for discharge of a patient and to object to treatment on behalf of the patient. The Lasting Power of Attorney could nominate an individual to act as nearest relative in the event of compulsory treatment or detention. This would provide consistency for the person with impaired capacity. The Mental Health Bill or the Act needs to be amended to recognise the LPA where a person has been nominated. Where a patient is compelled but has capacity to make decisions for himself, those views should be respected. That, however, is beyond the scope of this Bill.

12. *Better mutual recognition of international jurisdictions*

12.1 The notes state that the Bill recognises the Hague Convention of the International Protection of Adults 2000. However the mutual recognition of other jurisdictions does not appear on the face of the Bill (unlike the Scottish Act). This needs to be included in this legislation. Scottish lawyers already have difficulty enforcing their powers in England and Wales. This is a missed opportunity to embrace other jurisdictions.

13. *Fees*

13.1 Clause 44(3) specifies those who must be consulted on changes to court fees. The Law Society suggest this group should be wider as the issue relates to access to justice on which there are strong views, especially from user groups.

14. *Miscellaneous and Supplementary*

14.1 Clause 30(6) specifies those to have regard to a code practice. The Law Society is of the view this should also apply to donees of a lasting power of attorney and a court appointed deputy. It is not reasonable to expect persons under a general authority to have knowledge of any code of practice unless they are directly or indirectly remunerated. Therefore any instrument granting the power or contract for services should have an express term or should be endorsed so that "the deputy or donee must have regard to the code of practice". This should ensure that the decision-maker has notice of their duty to have regard to a code of practice in the exercise of their powers.

September 2003

Witnesses: **Ms Vicki Chapman**, Head of Law Reform, **Mr Peter Raymond**, Practising Solicitor, **Mr Niall Baker**, Practising Solicitor, and **Mr Luke Clements**, Practising Solicitor, The Law Society, examined.

Q544 Chairman: Welcome. Thank you for attending and for your written evidence. This session is open to the public and it is being recorded for broadcasting. There will be a transcript of the evidence which will be published with the report and you will be given a chance to check it for accuracy. If we are unable to go through all the questions or if there are any other points which arise in the discussions which you wish to address, perhaps you would be kind enough to write to us after the meeting. We are not here to write a White Paper on mental incapacity, we are here to deal with a draft Bill and all our questions are structured around the structure of the Bill. Perhaps you would like to start by introducing yourselves.

Mr Clements: I am Luke Clements, a solicitor. Perhaps I will let my colleagues introduce themselves.

Mr Raymond: I am Peter Raymond, a solicitor from Tunbridge Wells.

Mr Baker: I am Niall Baker, a solicitor from Sheffield.

Ms Chapman: I am Vicki Chapman, Head of Law Reform at The Law Society.

Q545 Chairman: Thank you very much. What is the value of the draft Bill beyond putting into statute what is already encompassed by common law?

Mr Clements: I think we would have to answer that by saying that it is in fact two questions. The first is it implies that the common law already deals with many of the issues in the Bill which we do not believe to be the case, but it also suggests that the common law is an adequate substitute for legislation. The Law Society believe that in general that is not the case. There may be situations where it is better to leave a matter in the common law—perhaps a fast moving or particularly controversial area which may

be the case in parts of this Bill. In general we believe that there are very strong policy grounds for having in statute, principles that may be distributed through the common law. I deal a lot with the poorer end of the market, if I might put it that way, with social workers and health care professionals, with people who do not have money but have particularly serious problems and in my view 95% or over of social workers, health professionals and carers have not the slightest idea what the common law situation is, they do not know what the principles are, and if you were to say the principles are "best interests" then in my view they would think best interests is a paternalistic view—it is what we often call the lettuce and the jelly situation.

Q546 Chairman: Perhaps you could explain that, please.

Mr Clements: If you have a client who has a severe learning disability or is confused, what is in their best interests, is it lettuce or is it jelly? Many people would say lettuce is in their best interests because it is good for you and what have you, but if this person is an adult of some age they may prefer jelly, and it is a hugely important issue. I think what we want to get across is how important language is. I know it may be an area where one says this is just semantics, but it is incredibly important to get across to the general public that this is a Bill about rights, rights for people with mental incapacity and it is not the "state knows best" or the "carer knows best". This is empowering people with limited capacity and therefore we need to have principles, not best interests and those principles need to be set out in the statutes so people know what they are, very much like the Children Act transformed what was a very uncertain position in the mid-1980s. In the mid-1980s the common law dealt with the principles of

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children and many very fine judgments have been made regarding what the principles should be, but most professionals were in the dark on that. The Children Act transformed that and now most professionals, if you say to them “what is the situation?”—would say “the check-list”.

Q547 Chairman: The check-list in the Bill of best interests, are they the same as those principles or do you want the principles set out?

Mr Clements: We welcome the categories that are called best interests. We have severe reservations about calling them “best interests” because of the jelly and the lettuce phenomenon.

Q548 Chairman: What is the term you would use?

Mr Clements: We would call them “general principles”, very much along the Scottish line and I think we would have to say that these general principles would not just apply to one category of people who have got mental incapacity, they would have to apply to all human beings and they must be compatible with the European Convention. Therefore they must start from the “no order” principle—which is that the state should not interfere in people’s lives unless there is strong grounds, not on the balance of probabilities. So there is a presumption in terms of “no order” and there should be the “least restrictive interference”.

Q549 Baroness McIntosh of Hudnall: You said this is a Bill about the rights for people with mental incapacity. I wanted to ask you whether you mean it *should* be a Bill about rights for people with mental incapacity or it is one in its present condition. It was put to us yesterday by witnesses from the Association of Directors of Social Services that the danger that the Bill stood in was that if left as it was it might become a charter for carers and service providers rather than for service users.

Mr Clements: I have to say at the very outset that The Law Society very warmly welcomes this Bill and we do believe that it is an incredibly positive statement. As we give evidence and when we talk amongst ourselves we must keep reminding ourselves of the fact that we are in favour of this Bill but we do have certain reservations about it. The biggest reservation we have is the absence of public law protection for people with limited or no realistic mental capacity. I think the Bill is about the rights of incapacitated people, but it is a major concern to us that it does not have more protection for people. In my area of expertise, which is people who do not have financial assets but who have capacity difficulties, I think that abuse, sexual and physical, is endemic, it is a very wide situation and it is not discussed. My colleagues, Peter and Niall, would say that financial abuse is probably endemic and therefore there is an absolute need for protection, but we do welcome this Bill and we do strongly congratulate the Government or whoever for bringing these things forward.

Q550 Chairman: Is the implication of what you are saying that if the protection is not in the Bill then the abuse, if it is not affected by the rest of the Bill, would go on?

Mr Clements: I fear that the abuse will go on whether it is in the Bill or not, but at the moment I am continually being confronted by carers and social workers who are aware of the abuse, but the police do not think there is enough evidence and they feel powerless. There is a procedure that the High Court is developing and the Lord Justice Sedley said the need to develop it was because Parliament has been silent and there is a need for somebody to do something, but that means going to the Family Division of the High Court and that is very expensive. We are very concerned about this situation.

Q551 Baroness Wilkins: Do you feel that if best interests is replaced by your principles statement then that would meet the fears of many of the user groups who say this as a very repressive measure at the moment? Do you think one could then sell it and that it would be seen as a Bill that was protecting their rights rather than diminishing them?

Mr Clements: I think so. I think that words are incredibly important in this area and I think principles is really fundamental because I think most professionals will only know one thing, “best interests” and it connotes my headmaster talking to me rather than someone who is empowering me. I do not think that would address all of these issues. The general authority is something that I think many self-advocacy organisations will have reservations about and I think we would have reservations about that unless there is some counter-balancing remedy for abuse. So I think it would be twin-fold, it would have to have the general principles which would have to be largely along the Scottish model of “no interference” and so on and also some powerful remedies such as anti-abuse and probably advocacy, including self-advocacy.

Q552 Baroness Fookes: Would you still have objection to the term best interests if it was much more clearly detailed what is meant in terms of the principles and what should inform it?

Mr Clements: I am sorry to say we would.

Chairman: I am afraid we will have to stop for a few minutes while we have a Commons vote.

The Committee suspended for a division.

Chairman: Perhaps I could just ask Baroness Fookes to repeat her question which you had just started to answer.

Q553 Baroness Fookes: You obviously do not care for the best interests principle. Would you be more accepting of it if it were hedged about with general principles and very much more information as to how it is to be interpreted?

Mr Clements: There are two issues that you are asking me to address. We think words in this area are very important because there are six million carers, there is hundreds of thousands of social and health

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care professionals and if and when, we hope, this Bill becomes law they may get a bit of training on this but it will be rudimentary and something like a phrase best interests will stick and we do not think that that is right at all. We believe there are principles that should inform and empower. We support those principles that are under the heading best interests in this Bill but we would add to them particularly the two that I have mentioned that are in the Scottish Bill, which is (a) no intervention unless it is clearly demonstrated to be to the advantage, so the no order principle—

Q554 Baroness Fookes: To the benefit?

Mr Clements: Yes, quite. Secondly, that any intervention should be the least restrictive intervention—both of which flow from the Human Rights Act anyway.

Q555 Mrs Browning: You have made clear your support for the Scottish legislation in terms of general principles, is that correct?

Mr Clements: Yes.

Q556 Mrs Browning: You think we should look again at that in terms of this particular proposal in the Bill.

Mr Clements: Yes.

Q557 Mrs Browning: Why is it that you feel one should distinguish between individuals with an acquired mental impairment and those that are born with impaired capacity given that the draft Bill requires every assessment of capacity to be time and precision specific?

Mr Clements: That is a very good point. It may be that in our submission we did not express that as elegantly as we ought to. Again, words and meanings have particular importance here. We have a perception that some aspects of this Bill have been misconstrued by certain sections and one of them relates to the fact that we are dealing with two groups. In my opinion one group has effectively no mental capacity on significant decisions and the other group who have limited capacity, who could make decisions on certain issues—and with assistance and encouragement could make more.

Q558 Mrs Browning: Just tell me which category you are putting them into. You say one group has no mental capacity. Which group are you saying has no mental capacity?

Mr Clements: I am saying on certain issues some people would have effectively no mental capacity, say an elderly person with advanced Alzheimer's disease. In that area with a progressive illness one might have problems. A younger person or middle aged or older person with learning disabilities may have limited capacity on certain areas and on all areas would have quite a lot to contribute towards a decision. These two groups are inevitably dealt with in this Bill. The group that is capable of self-advocacy to a degree is feeling that they are being dealt with as though they have no capacity at all. We were trying to express in our submission that these

are separate categories, of course they mesh into each other and somehow there would have to be a mechanism to explain that they would have to be dealt with differently because the principles would stack up differently for both of them and it is that merger of these two groups that has perhaps caused some of the disquiet.

Q559 Mrs Browning: I am still not quite clear in my mind why you differentiate between acquired impairment and those who are born with it. When a child is born with a learning disability, for example, there will be some people who will be on the spectrum and although they are born with a learning disability and will inevitably die with a learning disability, in between there are all sorts of situations that can improve their ability to contribute towards decision-making. For example, there is the technology that is used for people without any speech or hearing and things like that and the support packages that can make a huge difference to someone's ability to live independently or not, and resources has been a big issue for us in terms of whether what is deliverable has really got the resource base to it. I am still not quite sure why you differentiate between born and acquired.

Mr Clements: I think that is the inelegant bit in our submission.

Q560 Mrs Browning: Would you wish to withdraw that?

Mr Clements: I accept what you say on that issue.

Q561 Baroness Fookes: Inelegant or inaccurate?

Mr Clements: Inappropriate.

Q562 Huw Irranca-Davies: I am still unclear. You mentioned earlier on the general principles. If there were general principles that were underwriting this Bill in a similar way to Scottish legislation then those could be fully applied regardless of age, they are in effect general principles to apply to any human being and yet, if I understood you correctly, what you are suggesting is that there is a different approach amongst these two different user groups and those general principles need to be written differently and framed differently for those two groups. I may be misunderstanding you.

Mr Clements: Again, I may have been inelegant. What I was trying to say there is that these two groups inevitably are dealt with by the Bill. I think the Bill has to deal with a wide spectrum of incapacity problems. Somebody at one end of the spectrum who really has very limited capacity due to a progressive form of dementia and is elderly and a younger person that is born with learning disabilities you would apply the same principles to but the outcome would be different and that must be the case.

Q563 Mrs Humble: I am afraid I am still not clear what you are saying here. Why should the outcome be different? Taking each decision separately and first of all determining whether or not an individual has capacity and then looking at whether or not they

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have the capacity to make a decision in that particular circumstance, how can the outcome of applying the best interests principle be different for people whether they were born with a disability or acquired it through accident or illness?

Mr Clements: I have accepted that that was inaccurate. That distinction between those two groups was inappropriate for us to put in the submission and I have accepted that. What happened is that when we made the submission we put in two groups, which was the one that had no capacity effectively and the one that had only limited incapacity and those two groups are dealt with in the Bill. The inclusion of the acquired deficiency I think was unhelpful.

Q564 Laura Moffatt: We have talked a little bit about the general principles today and in actual fact we have spoken a lot about it in this Committee and we are really trying to make sure this Bill is in good order. Could you give us any other examples from any other jurisdiction or the Scottish Bill as it exists that should be included or that you believe would strengthen this Bill? As I have said, we have spoken about the fact that you much prefer having some sort of general principle over best interests. Is there any other example you can give us?

Mr Clements: We have not found any from any other jurisdiction in our searches. I am not saying it is exhaustive but it has been quite thorough.

Q565 Laura Moffatt: Could you say where?

Mr Clements: We looked at the jurisdictions of the United States, Canada and Australia and New Zealand. As I understand it New Zealand was the blueprint for the Scottish legislation and is to be preferred. We accept the best interests list that appears in this Bill and we welcomed it when the Law Commission published it and effectively it is the same as the Law Commission's. Having had the benefit of what has happened in Scotland, there is a convincing case for the inclusion of the "no order" principle, which effectively is you should not make an order unless there ought to be one, that the least restrictive interference will be appropriate. The other one that I can think of which would appear in the Children Act is the issue of delay. The general principle of delay operates against the interests of someone: it is another general principle.

Q566 Laura Moffatt: In your very helpful written submission you suggest some different ideas for the Bill that come from The Law Society and they are not taken from any other Bill apart from the general principle issue from the Scottish Act, is that right?

Mr Clements: We looked at other areas, but insofar as it has been formed by anything substantial, it has been from the Scottish experience.

Q567 Baroness Knight of Collingtree: Coming back to this question that you raised of the difficulties of the varying degrees even at varying times of people to make decisions, I would like to ask you if you think that the draft Bill as it stands places sufficient

emphasis on the need to deal with that particular difficulty and the need to facilitate the communications of people who do have incapacity?

Mr Clements: The Scottish Act is slightly stronger on this. We very much welcome what is in the Bill, it is very much in accordance with what the Law Commission did. The Scottish Act has a line and a half more about the efforts that one should make to communicate and we would welcome that expansion. We welcomed the fact that in this Bill there is that emphasis but we think it could be tightened up a bit.

Q568 Baroness Knight of Collingtree: This follows something about which you will not be aware but it was something that was said to us yesterday. In your submission you say a person should be free to take a risk, to make a capricious or bad decision or one that does not appear to be in their best interests so long as their capacity is not disproportionately impaired. We need to have a little clarification of that bearing in mind that we had some evidence yesterday that is rather different from that.

Mr Clements: I think the classic example will be the elderly frail person that wants to live at home and everybody says that it is in his/her best interests that he/she goes into a residential care home, or the family that is caring for somebody with learning disabilities that has views on those situations. These people should be allowed to take a risk.

Q569 Baroness Knight of Collingtree: Do you think, for instance, to cite a case that was put to us yesterday, that if someone meets a visitor at their door and after a short conversation writes a cheque for £5,000, there ought to be some level of interference with that person's doling out of their own funds or not?

Mr Clements: Yes.

Q570 Baroness Knight of Collingtree: You think there should be some interference with it?

Mr Clements: Yes. The issue here is what is proportional in any situation. It is part of the human condition to take risks and that is what makes our lives fulfilling and enjoyable. I fail to understand why the right to take risks and to do things on a whim should be taken away from one group of society, but obviously there are certain things that are outside it. If somebody has not got the capacity to make a decision about £5,000 then it should be a decision that is outwith their ability, they lack the capacity to do that.

Q571 Baroness Knight of Collingtree: You seem to be facing both ways on this. Is it not the case that a person has a right to dispose of what is their own in the way they think fit even if we do not think it is fit?

Mr Clements: Precisely. My colleagues understand money much more than I do, but what I would say is that of course you should have the ability to dispose of your bounty as you wish as long as you comprehend the implications of that situation. The capacity you need to give away £5,000 at law will be a different test to the capacity you would need to give

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away £1,000 or £5, but providing you have the capacity to do that we should allow people to do it. We all know lots of very mentally capable people who use their money irrationally.

Q572 Baroness Knight of Collingtree: Do you think the Bill actually does enough to make it easy for decisions that people make to be properly conveyed? Is it easy enough as it is or should we do more?

Mr Clements: We should do more to facilitate communication with people with that mental capacity, yes. As I say, the Scottish Act has an additional part about trying to engage in communication and improve communication. I think it is the experience of all the people who have come into contact with learning disabilities that you need an enormous amount of time to understand the level at which they are functioning and that is something that cannot really be over-estimated, the amount of time you need to spend with somebody which often lawyers do not have and that needs to be stressed in the Bill.

Q573 Mrs Browning: I just want to test where you are placing the balance between the right of the individual to take risks and the responsibility that may rest with social services, close relatives and others particularly in the case that you yourself gave us of the elderly person who wants to stay at home and categorically refuses to go into residential care. We all know feisty old ducks, God Bless them, who say, "I'm saying here and I don't care what the risk is, I'm going to carry on", and that is fine, they clearly have made a considered decision about it. More common is the case of the elderly frail person with a deteriorating ability to feed themselves properly, an increasing risk of falling, perhaps a history of starting to fall and sometimes when they have the little buttons round their neck and they do fall, they forget they have got one so they just lie there on the floor until somebody happens to find them maybe a day or two later. Where is the balance there?

Mr Clements: It is very difficult to draw, is it not?

Q574 Mrs Browning: It is.

Mr Clements: What I would always say is that the ability to have somebody make a capricious decision is not unconstrained in the sense that I think we all have a duty to cajole and give advice and give strong views to people like that. With many of my clients I would say that this is ridiculous. It is not unreasonable to cajole somebody, to give them advice because we influence all the people we know about the decisions they are making. I would not say to my daughters, "It's up to you, I am not going to give you any advice", and I think that we have the right to do that to people with learning difficulties and elderly people as well. We can give them robust advice and try and cajole them to do what we want but ultimately it is their decision.

Q575 Lord Rix: You have concentrated a little bit on money and elderly people in terms of freedom of expression and freedom to spend it. Suppose a

decision is taken by a person to live in the utmost squalor, with animals around the place being fed all the time and all the other things which happen when you live in conditions which could adversely affect your health, if that person appear to be in full control of their faculties, how do you begin to gauge when you have to take steps to improve matters with regard to their living conditions?

Mr Clements: You are asking some of the very most difficult questions and they are probably social work not legal questions. Under the National Assistance Act, section 47, there is power for authorities to intervene in situations where there is an environmental health problem. As you may well know, the research shows that when local authorities do intervene to remove frail people from squalor situations they tend to die very quickly.

Q576 Lord Rix: They may not be a frail elderly person, they may well be someone in middle years, even younger.

Mr Clements: Most social services directors would say that they have used their powers under section 47 in situations where it was the only thing they could do and they did effect positive change. There is therefore clearly a need for a power of that type.

Q577 Lord Rix: And you believe that this Bill allows that to happen?

Mr Clements: The Bill does not affect the National Assistance Act. Presumably this Bill would leave that intact because these people would have capacity and this Bill is not dealing with people that have capacity, therefore the local authority would not be able to use any other power than the National Assistance Act.

Q578 Mrs Browning: Is it not ironic that in those sort of cases—and we have all seen them—the RSPCA would step in to protect the animals long before anybody would step in to protect the person?

Mr Clements: Yes.

Q579 Mrs Browning: Is there not something rather worrying about that?

Mr Clements: There certainly is.

Q580 Chairman: The presumption of capacity is clearly important, but in the example of someone who makes unwise decisions should there be a shift in the burden of proof? The Bill uses the common law principle of proof. Do you think in those cases there should be a shift in the burden of proof in determining incapacity?

Mr Clements: This is completely off the top of my head, but I would have thought that would be completely untenable.

Q581 Chairman: Why?

Mr Clements: I think it would violate the European Convention on Human Rights, Article 1 of the First Protocol. You would then get into the situation of saying what you mean by an irrational decision. What was irrational 150 years ago is now considered sane.

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Q582 Chairman: But even now under common law judges have to make that sort of judgment.

Mr Clements: As far as I know every common law jurisdiction has a presumption of capacity for adults and I would have thought that is true of the continental jurisdictions as well.

Q583 Baroness Wilkins: This law would be very dependent on the codes of practice that we have not seen yet. Do you think the draft Bill is too dependent on them?

Mr Clements: Yes, we do. That has two aspects to it. Our view is that inevitably a lot of this would have to be in the Code of Practice. The Code of Practice that we have in mind is a bit like the Scottish system, although that is quite dense, but the codes of practice that come within the Disability Discrimination Act would be very helpful indeed in giving real life situations. We do believe that there are a number of areas where the detail could be in the Bill rather than having to wait to see what is in the code. The thing we most regret is the fact that in order to understand this Bill we would have to see the draft code. In fact—and I do not even want to get drawn into this unless you want to—we would have to see the Draft Mental Health Bill as well because these three things have got to mesh. This is a Bill that is very much dependent upon the code.

Chairman: That might be a Bill too far!

Q584 Baroness Wilkins: Could you say where in the Bill you would like the code to be put instead?

Mr Clements: We have problems with the general authority. The general authority effectively allows anybody that provides care, which is not defined, to do anything that they think effectively is reasonable with a few exemptions. There is a degree of a lack of proportionality there in that we have considered that perhaps there should be some limit on the amount of property that somebody could divest, whether they could sell a house or not and certain things like that. Certain limitations on that general authority we think should be placed in the Bill rather than in the code because the general authority as it stands is almost a blank cheque.

Stephen Hesford: You have mentioned the Mental Health Act/Bill and it is an area that we were not otherwise intending to cover, but it is an area we covered previously. It is an area that we may have to return to. Could I direct you to clause 27. Bearing in mind your comment and the Chairman is right that we cannot go down the road of examining the Mental Health Bill—

Chairman: There is not one at the moment.

Q585 Stephen Hesford: There have been various draft Bills, there certainly is an Act in existence at the moment which may or may not inform the process. Do you have any comments about clause 27?

Mr Clements: Only that this is a classic example of where these two pieces of law have got to mesh. In this situation you might have certain groups excluded from both forms of protection. I have seen the comment on that and that is a drafting matter that would have to be dealt with in the sense of which

piece of legislation it would fall within. We are particularly concerned and I am sure that those drafting the Bill are also very aware of problems with clause 7 which is restrictions on liberty because it does authorise people to be detained in exceptional circumstances. Is that something that is to be dealt with by the Mental Health Act or is it something that is going to be dealt with by the Incapacity Act? We have had a case in the European Court of Human Rights which was known in the House of Lords as the *Bournewood* case and you have what is called the “*Bournewood* gap”, under what piece of legislation will somebody who is mentally incapable be incapable of being detained? This legislation seems to suggest that it would be possible to detain somebody with a mental incapacity under clause 7, but it describes a procedure. Article 5 of the Convention says there should be a procedure prescribed by law. It also does not deal with the public-private point of view. If it is a local authority that is detaining somebody, maybe locking them in their residential home because they are short staffed and there is an emergency then it would be covered here, but that would be a violation of Article 5 because it is a local authority. If it was a private authority, which is not covered by the Human Rights Act, then it would not. These are areas which are just difficult drafting areas, these concepts have to be dealt with by these two Bills going in tandem.

Q586 Stephen Hesford: Whilst you have described a situation as a potential problem of the Act not being symbiotic but running in parallel and leaving a potential working gap, my question was have you any comment on clause 27? The answer may be no.

Mr Clements: I have not had any particular insight into that. I have seen evidence that has been given to this Committee from your session with the Scottish delegates who point to that as being a lacuna, that there could be a big problem and I agree with that insofar as I am not a mental health expert.

Q587 Chairman: The situation that you have been describing is one where you see this Bill becoming law, however amended by our work and the Mental Health Act 1983 being in force alongside that. That is the situation you are describing, is that right? We are not talking about mental health Bills which are drafted or not drafted, but the situation could be that this Bill, however amended, and the Mental Health Act 1983—

Mr Clements: I always assume that the Government will give more priority to the Mental Health Bill than this Bill, I fear to say and therefore the Mental Health Bill would come into force before this one.

Q588 Chairman: If it did not, if the situation is that we had this Bill and the Mental Health Act of 1983, what is the problem in practice?

Mr Clements: The problem in practice would be the problem identified by the *Bournewood* situation and it will have to be addressed no matter what the outcome and the Government has committed itself to addressing that issue.

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Q589 Baroness Fookes: You clearly disapprove of general authority as currently drafted since you referred to it as a “blank cheque”. Do you envisage certain restrictions being put upon it and, if so, what might they be?

Mr Clements: I have to restate continually that The Law Society warmly welcomes this Bill. Like everybody else, we have views about what we would also like to see in it. We are concerned about the general authority because there is no counterbalancing public law protection of rights and so if somebody abuses the general authority there seems to be no effective remedy. If there is to be no public protection provisions in this Bill then we would not like to see what could potentially be a blank cheque and to have some restrictions on the amount of money that could be given away, for example. Potentially you could give a house away and that clearly is not the intention here because I think this is meant to deal with the very real problem that carers have day-to-day when dealing with an elderly relative who has got some money and you cannot go through the paraphernalia of an application to the court. We would like it to be somehow kept on a local, small level and we do not see that the code can do that. So we would like to have some restrictions on the general authority in terms of the quantity of assets that can be divested and in our submission we say that it would not be necessary to pledge credit for instance, to say that their credit card will do all this: that there are limitations on this authority.

Q590 Baroness Fookes: Could you give us any more detail at a later stage, because I imagine that is not the only thing you would be concerned about or would you wish to make those who exercise this general authority more answerable in some way? Because this is a draft Bill anyone could suggest anything they like to improve it.

Mr Raymond: I think that what we would hope for is—this is in an ideal world and we do not live in an ideal world—some form of monitoring of what people do in the same way that our Scottish colleagues do. They have a public guardian and the public guardian has the ability to step in even if he only has a belief that something may not be quite right. He does not have to have evidence that things are wrong or that there is financial abuse, but he has the ability to say if he thinks that things are not as they should be and he has cited some cases to me. One of them was where the patient with a large estate was living in secondhand clothes which were acquired for him from friends and relations whereas the person with responsibility for managing the affairs was running around in a brand new German motorcar. There was a clear indication that things were not right but there was no evidence that the money to buy the car had come from the patient's estate. That ability to investigate and require accounts would be ideal. In the sense that the general authority confers the ability to spend the patient's money or pledge credit, I think we would be looking for that to be removed and replaced by something where the only ability to spend the money came from the attorney, so the attorney would be in charge of

the finances and it would be one person who is responsible for the money and property side of things, whereas the general authority was relating really to care and health matters.

Q591 Chairman: You referred to the public guardian, but the points under clause 48, the “Functions of the Public Guardian”, are you saying that those are not wide enough, that they should be given more power?

Mr Raymond: I am saying that under the powers given to the public guardian in Scotland he has the ability to investigate circumstances and to work with local authorities and the Mental Welfare Commission where circumstances suggest that things are not right. Under our system there has to be clear evidence that there has been impropriety and it is not the same, you have to go to the court, which is an expensive process and what we are trying to do is make it more workable for every day problems that arise.

Q592 Chairman: It does say that one could confer on the public guardian other functions in connection with this Act by regulation. That might meet your concern.

Mr Raymond: Yes. I think what I am really concerned about is that we should not have a situation where you either had to go to the court or you could not have the circumstances investigated and there should be a duty for the public guardian to investigate. It is left a bit in the air at the moment.

Q593 Baroness Fookes: But you are looking for some person or some power to oversee those who exercise general authority?

Mr Raymond: To ensure that we do not have the amount of abuse that we have at the moment, yes.

Q594 Huw Irranca-Davies: I have two points I would like to ask you about. First of all, at the beginning of this particular discussion I was curious as to whether under section 6(6), where it says, “The general authority is subject to the provisions of this Act and, in particular, to section 4 (best interests)” part of the solution to what you were seeking would be if that were replaced by the phrase “... in particular, to section 4 (general principles)” and to what extent that would have an impact on what you are seeking. I think you have answered that. You were seeking absolutely concrete tangible limitations in some ways which brings me on to the second possibility. Those will fluctuate over time and by necessity goes back to our earlier discussion about where the soft law in the Code of Practice lies and where the hard law in the face of the Bill lies. If there was something within section 7, “Restrictions on the general authority”, which laid that out there would not be limitations determined by the sub-agent, that would fluctuate from time to time and these will be set out in codes of practice. Would that then, if it put the rest of the detail into the codes of practice, be sufficient for what you were seeking?

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Mr Clements: The Law Society has always welcomed the general authority on the basis that there would also be a public law anti-abuse provision and we are now being asked to look at a Bill which has one without the other and we are not surprised that a number of organisations are concerned because it appears slightly lopsided. We are incredibly eager for this Bill to become law and so we would try to remedy that if we cannot have public law provisions by the sort of mechanism you are talking about. There are procedures for particular orders in the Court of Protection provided they are under £16,000 or something, so we are clearly familiar in court proceedings that courts have jurisdiction for certain figures, so it must be capable, if the Government does not wish to publish a Bill for public protection measures, to bring in the mechanisms, as you are suggesting.

Q595 Baroness Knight of Collingtree: This was following on something that Baroness Fookes asked you and the way you answered it. Of course we hang on your every word, but there are occasions when you puzzle us because in your submission about decision-makers, you suggest that throughout the Bill, the phrase should read, "the person reasonably believes and it is objectively reasonable to hold this view". Are you asking for two lots of people, one person to make the decision who reasonably believes, but then how can you say, "... and it is objectively reasonable to hold this view"? If one person makes the decision, are you asking for another one to come along and say, "Well, wait a minute, I am not sure that objectively that is reasonable"?

Mr Clements: Yes, that is a very good point. What we are merely asking is that this Bill be drafted consistently with other Bills. In the Disability Discrimination Act, that is the phrase that is used, but if somebody wants to discriminate, then they have to justify it, but they must also believe it to be necessary and objectively it has got to be reasonable. I could say that I am acting for my mother and it really would make her very happy if I had a new Ferrari. Now, I honestly believe that and she loves me dearly, so that would be something that I honestly believe and for the Act that would be good enough, but what we are saying is that it should also be objectively reasonable to somebody else. Now, that is not new. It is a drafting mechanism that is already used and, as I said, the Disability Discrimination Act uses that precise wording.

Lord Rix: You mean you get a Jaguar instead, do you!

Q596 Chairman: If you say it is objective, there must be some criteria. There must be some criteria by which you measure the objectiveness.

Mr Clements: Yes, one would hope that the code of practice would include that as it does in the Disability Discrimination Act. The examples in the DDA are saying, "I think it is quite reasonable to refuse these people access to a restaurant because they look strange and they would upset my other clients". Now, the person will honestly believe that,

but objectively that may not be measurable. I understand that it is a difficult test, but if all somebody has to go into court and say is, "I honestly believed what I was doing", then that is not an adequate safeguard for somebody who has no capacity.

Q597 Baroness Knight of Collingtree: But do you not reach your reasonable decision objectively?

Mr Clements: I see what you are saying. I do not honestly think that it is actually an incongruous concept. Somebody must believe what they are doing, but that cannot be sufficient. Sincerity alone is not a defence in law.

Baroness Knight of Collingtree: Well, I can only put on record that I think it is a rather difficult thing to try to do.

Q598 Mrs Browning: I think we all understand in this place that if you are too prescriptive in what you write into the face of the Bill, you end up with some very difficult problems later in the way that Bill is implemented and then challenged. Is it not the case that those two words, which we have heard quite a bit of this afternoon, "reasonable" and "proportional", are the very oxygen by which lawyers make their money because it is usually the interpretation of those two words that brings a case to court in the first place?

Mr Clements: But it is also the oxygen of society. In the pluralistic society people have got to be allowed a very large margin in what they do, "what is reasonable", but in some areas where you have very vulnerable people, that is not good enough to be sincere and it has also got to be objective. There is some higher standard that in certain situations the court must account for.

Mrs Browning: I am just testing you!

Q599 Baroness McIntosh of Hudnall: But are we not being told that this is wording which is used elsewhere in legislation which has similar objectives and that we may want to challenge the use of that wording in general terms, but this is not an appropriate moment in time to do that? What we are being asked to consider is the compatibility between the situation, say, of people who are protected by the Disability Discrimination Act and the situation of those who would be protected under this Act and that there should be some measurable relationship between the standards of proof that are used in both situations. Is that not so?

Mr Clements: Yes, I wish I had said that!

Q600 Stephen Hesford: Well, can I disagree with Baroness McIntosh because I think it is more fundamental than that. It is a very well-worn phrase in law, the reasonableness test, and the reasonableness test is objective. It is not subjective, it is objective. Your guy with the Ferrari would not get away with just an honest belief if it was not based on a reasonable description of the relationship that he had with his mother, so it is otiose. What you are arguing seems to me completely otiose, not necessary, because it is a well-worn phrase which is

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used in legislation up and down the country and has been used for a long, long time. What else is a reasonableness test other than objective?

Mr Clements: This Act does not say that it has got to be reasonable. It says that the person must honestly believe that it is reasonable.

Q601 Baroness McIntosh of Hudnall: Reasonably believe.

Mr Clements: They believe it is reasonable. They are sincere.

Stephen Hesford: Where are we?

Huw Irranca-Davies: It is 6(1)(a).

Q602 Stephen Hesford: There is nothing about his belief.

Mr Clements: The person reasonably believes what he does—

Stephen Hesford: It is not about an honest, mistaken or crazy belief, but it is reasonable belief.

Baroness Fookes: Which would then be tested in a court. Who decides what is reasonable?

Stephen Hesford: But it is often tested dangerously.

Baroness Fookes: Precisely.

Q603 Stephen Hesford: But this is an objective test; it is not a subjective test.

Mr Raymond: If you are looking at the provisions of 4(4) which refers to “reasonably believes”, it is the person making the decision who “reasonably believes that what he does or decides is in the best interests of the person concerned”. Earlier in the clause there is a conflict with that, belief, because you have got, “the act must be done or the decision made in the person’s best interests”, the patient’s best interests. In subclause (1) it is saying that the act must be done in the person’s best interests, that is the patient, and in clause 4 there is a let-out because you are saying that the person making the decision reasonably believes that what he or she did was in the person’s, the patient’s best interests. So there is a conflict there in the wording, and I think you need to be looking at that and saying which rules. I think what we are saying is that 4(1) should prevail rather than 4(4).

Baroness Barker: We have had one group of people in our deliberations who have attacked the word “reasonably” and a second group of people who have attacked the word “belief”, so there is clearly a problem here. I have been thinking ever since they did that that what is not in clause 4 is any mention of the evidence as to why somebody believes something and reasonably believes something. I wonder whether, in your experience, a requirement to produce evidence to back up people would help.

Stephen Hesford: But that is what happens now. That is the whole point.

Baroness Barker: I am sure it does and I am sure it does in the courts, but the people who were raising these things were not lawyers. I am quite happy to take what you say as being a legal test, but it is not something that other users of this legislation appear to understand because we have had big representations on it, so I am trying to find a way—

Stephen Hesford: But is that because they lack capacity?

Chairman: It is the famous test of the man on the Clapham omnibus.

Stephen Hesford: Yes, exactly and he applies here.

Chairman: Exactly. I think probably we have had enough discussion on “reasonably” and we can now move on.

Q604 Huw Irranca-Davies: I would like to tie a couple of questions together because they do lead on and, to let you know where I am heading, this is to do with human rights as they affect people who lack capacity where a judgment is made and also Article 2 of the Convention on Human Rights. Perhaps I can start by asking a broad question. In your opinion, is this draft Bill compatible with the Human Rights Act 1998 and if not, what is going to be used?

Mr Clements: We have concerns over clause 7 and I think that those are accepted by the Government probably, that under clause 7 it effectively seeks to codify the common law of necessity. That I can, if it is necessary, detain you: but it says under the general authority that it does not authorise a person to restrict the liberty or movement whether or not he resists, under section 7(1), “unless the person reasonably believes that it is necessary to do so to avert a substantial risk of significant harm”. There is no requirement there that there be immediate power and it is also again a reasonable belief. We do not allow police officers to reasonably lock people up if they reasonably believe it is necessary and it has got to be objective, so we could perhaps return to this argument where I think we both stated our views and we agreed to differ. So we have reservations about that and there are two reservations in relation to that clause. If it is a public authority that is doing that, then Article 5 of the Convention says that there must be “a procedure” by which this happens and there is no procedure prescribed here and that is the Bournemouth gap problem. The other problem is what happens if it is an individual doing that because if it is an individual doing that, it may not be detention within the meaning of Article 5 because that has to be state detention, but it would be degrading treatment under Article 3 to lock somebody up. The court has repeatedly said that where somebody is exposed to risk of degrading treatment, Article 3, read with Article 1 of the Convention, requires there to be laws to deal with that—and there are no abuse provisions in this Act. Therefore, it seems to the Law Society that the absence of abuse provisions here are a problem. As we have heard, the Court of Appeal is trying to do its best, as they said in *Re F*, that since Parliament has not enacted any legislation, they will speak where Parliament has been silent and that is an unhappy situation where the courts are legislating to fill a gap, so we have reservations about that in particular. In our submission, we have pointed to a problem with appointeeships which I think is a clear violation of Article 6(1) in that the person who is the subject of an appointeeship, a social security order, has no recourse to an independent tribunal, which is probably a civil matter within the meaning of Article

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6. We have also significant reservations about the issue of access to court. Under Article 6 of the European Convention people should have access to court—it is within the concept of a fair hearing—and of course people with mental incapacity have huge barriers, social and legal barriers, to accessing court. One of them is the fact that there is no legal aid available in the current Court of Protection and in the case of *Airey v Ireland*, it suggested that that would probably be a violation of Article 6 again, so I think that those are the major concerns we have, substantive ones, regarding that.

Q605 Mrs Browning: Following on from that, last year the Government produced a draft Mental Health Bill which went out to consultation, but was not then presented in the Queen's Speech and there was some consideration that if the Incapacity Bill came forward first before a new Mental Health Bill, it would obviate the need for a new Mental Health Bill. One of the most contentious issues in that draft Mental Health Bill was about matters that surrounded things like the definition of "personality disorder" and new powers that might be given to detain people often for an indefinite period based not on any harm they had done anybody or themselves, but on a perceived situation, say, by a psychiatrist. Now, I did quite a lot of work on that at the time because I thought it was a Bill that was going to come forward. I was very concerned at the lack of definition of "personality disorder", it appears to be a spectrum, and I was very concerned about that part of the Bill for that reason. Is there anything in this Bill, including clause 7 which you have mentioned, which would allow that situation to progress in this Bill in the way that it was perceived and written in the draft Mental Health Bill which we saw last year?

Mr Clements: I am not primarily a mental health expert, but we are fairly comfortable with the definition of "incapacity" in this Act because it is a functional definition rather than an organic definition, so I do not think that the problems as we perceived in the draft Mental Health Bill, of which the Law Society has been extremely critical, exist in this definition.

Q606 Huw Irranca-Davies: Could I put a proposal to you which you may want to take up. You went through quite a range there of areas of concern with human rights compatibility and you have rightly highlighted those in your written submission. I am just wondering whether you would want the opportunity to come back with a further written submission expanding in some detail on what you consider. I know I am throwing this ball straight at you, but you certainly went through it in some more detail than you have put in your written submission.

Mr Clements: I think the answer to that must be that we would be delighted!

Q607 Huw Irranca-Davies: Thank you. If I can lead on from that to the controversial issue of Article 2 of the European Convention on Human Rights, that

although the state has an obligation to protect life, an individual can choose not to uphold that right, is this your interpretation of Article 2?

Mr Clements: Yes.

Q608 Huw Irranca-Davies: How does this Bill sit with that?

Ms Chapman: Perhaps I can deal with that. We were going to come to this with some later questions. At the Law Society we do not have a policy on this at the moment. We recognise that there are strongly held views on both sides. Our view at the moment is that it is vital to get this Incapacity Bill through Parliament and we think this would be facilitated by the broadest possible consensus behind the Bill. We realise this might not be possible if there is an argument or a debate around the use of advance directives. We would accept, we could live with the provisions on advance directives being removed from the Bill. We do not want this issue to damage the chances of us getting legislation in what we think is a really important area on the statute book. Having said that, it is the Law Society's position and if any of my colleagues want to comment on this from a personal point of view, that would be fine.

Mr Raymond: There is nothing in statute on this subject and we are anxious to avoid a situation, as was suggested earlier, that we might be here to feather the nest of lawyers in the future by prompting a lot of case law. There are a lot of people in the country who want to make provision of this kind. It is a very difficult area, it is very emotive and people hold strong views on both sides, as has been said, and it is extremely difficult to bring forward a form of words which manages to produce the answer which one body of opinion wants without crossing that very thin line of what is and is not acceptable. It has occurred to us that it might be possible to have a standard form of words which would be produced in a way similar to the enduring powers of attorney form which would be acceptable and would be accepted by all sides, but whether that is living in cloud cuckoo land, I do not know, but that would be an ideal situation where we could have a standard form of words. I do not know if we could reach that, but that certainly would satisfy one body of opinion.

Q609 Lord Rix: I personally believe that an advance directive or a living will is possible to write which is sufficiently liberal to allow the medical profession and your relatives, considerable latitude when it comes to the last days of your life, I also believe that advance directives to refuse treatment could be worded in such a way in the Bill as to make them acceptable to 90% of the public, if not everyone, and do remember that advance directives are voluntary. You would like to see them removed entirely from the Bill, would you?

Mr Raymond: No, that is not what I am saying.

Ms Chapman: I think as the Law Society we are not saying that. What we are saying is that we would not like to see the law flounder on this issue and if they were removed, we could live with that rather than seeing this ending up causing the Bill not to proceed.

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Mr Raymond: I was expressing a personal view, that perhaps if advance decisions or advance directives, whatever you call them, proceed, we would want to have it as non-contentious as possible because we would not want to see a situation where every time it had to go to the court to decide because that would not be a satisfactory solution.

Q610 Lord Rix: I would agree with that, but would it be possible, and I have given you some very rough wording just now, to take that away along with submissions which have been made by, I think, the Terence Higgins Trust and others and to come back with a response to this Committee with changes which you would like to see regarding advance directives on the face of the Bill?

Mr Raymond: I think the difficulty is, as has been said, that the Law Society would not want to be making a statement on behalf of the profession about advance directives, but I think if we put forward personal views, that would be different, and we are very happy to do that on a personal basis.

Q611 Chairman: Would you agree that if there was an approach, it would be better dealt with in a code of practice rather than on the face of the Bill because a legal challenge could lead to judicial review, whereas a code of practice could indicate the sorts of things that should be included in that and it would be safer?

Mr Raymond: I think the difficulty, Chairman, is that at the moment we have a situation where advance directives have no statutory authority and people who want to make such a directive do so in the knowledge or the lack of knowledge of certainty. They do not have the ability to say whether a particular doctor would carry out their wishes or not because some doctors will accept what the patient has said and others will look at the Hippocratic Oath and say that they have to preserve life at all costs. It is very difficult at the moment and, therefore, I think if there was something in the Bill—this is a personal view—that would make that position clear.

Q612 Baroness Fookes: One could place the directives on a statutory basis inasmuch as you include them, but they would not necessarily have to be obligatory. What about having them in an advisory form?

Mr Raymond: I think that would be fine. I have no problem with that personally.

Q613 Baroness Knight of Collingtree: If that is accepted, could we always bear in mind that there is another side to this? There may well be patients who do wish to be kept alive and that if one side was to be catered for, then the other side, a card-carrying person who says, "If I am unable to speak or am in a coma, I do want to be kept alive", would that not be a good thing to bear in mind at the same time? We are not just looking at one side.

Mr Raymond: No, or you could look at it that people who wanted to have an advance directive would have to opt in and everybody else would have been deemed to have opted out.

Q614 Baroness Knight of Collingtree: That was not the question I asked.

Mr Raymond: I know!

Baroness Knight of Collingtree: It would be better if you stuck to what I asked you as opposed to what you would like me to ask!

Mrs Browning: I am a little concerned about what Baroness Knight has just said because doctors, one imagines, I am pretty sure, would do all that they could to preserve life, that is the Hippocratic Oath, but there does come a point at which doctors have to use their judgment, for example, as to whether to give an operation to somebody who quite clearly may not benefit from that operation, but would be kept alive as a result of it. I just wonder how difficult that would be, and kept alive to what extent? We all share the concern about the withdrawal, say, of food and liquids. I think it goes without saying that there has been a lot of debate about that aspect, but in terms of medical intervention, at what cost to the individual, because there may well be procedures that could be carried out if you have somebody back to theatre for whom clearly another operation is not going to work. It might keep them alive for another fortnight, but when do you actually stop chemotherapy or when does the chemotherapy itself become part of the problem?

Baroness Knight of Collingtree: But is it not the case these days that doctors no longer swear the Hippocratic Oath and it is not part of their training and some of them who do not accept it do not have to agree to it? I think if we imagine that all doctors are there with the Hippocratic Oath firmly in their backpack, we are wrong because they no longer sign up to it.

Q615 Chairman: Perhaps we should not debate this between ourselves! There was the example in the press recently of somebody whom I know very well who is extremely severely disabled and she was very, very ill with pneumonia in hospital, the doctors assumed she would not wish to be resuscitated because her quality of life was so poor, not with the pneumonia but with her disability. Of course she insisted that she wanted to be resuscitated and that is an example of what kind of impact this might have where it is the reversal of an advance refusal and it is an advance insistence. Is that right?

Mr Clements: There have been a number of disabled colleagues that I have, who found the Diane Pretty case was actually very harmful because there was some suggestion that we look down on people like that as though their life is not worth living effectively. Who are we to say? I want to reinforce what my colleague has just said. The Law Society was instrumental in trying to get the Law Commission to look at this area in 1995. We are dealing today with a group of people who do not vote, who do not have any political clout, who have really no legal rights whatsoever and it is of tremendous credit to Parliament today that it is actually legislating because there is no huge, overwhelming demand for this, although it severely affects the lives of countless thousands—indeed—of millions of people. Ever since this Bill was first

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drafted by the Law Commission, we have been plagued effectively by this issue of euthanasia and we are so desperate to get at least some aspects of this Bill that we would really forgo this aspect, although individually we have views. As the Law Society, this has been our constant aim for ten years and we have come so close and then again we have this debate where reasonable people on both sides can have views.

Q616 Jim Dowd: On this idea of advance refusals and now, as the Chairman has said, advance insistence, I put this proposition to you which is that I believe that the law should be no more intrusive in people's lives and certainly no more than the majority of the population thinks it need to be. If we have two categories, both advance refusals and advance insistence, will not the bulk of the population who would otherwise not be affected by this measure have a choice to make? Surely the position that we are admitting, unless there is strong evidence to the contrary, is that you would expect to have whatever medical treatment is possible rendered to you without having to sign a piece of paper in advance to declare it?

Mr Clements: Yes.

Q617 Baroness McIntosh of Hudnall: I wanted to ask you whether you thought that the provisions of the general authority increased the likelihood of the abuse that you referred to earlier in your evidence as endemic, the abuse of people with incapacity. I think what you have said since has indicated that on the whole you do think it is likely to increase that risk. Would that be a fair assessment?

Mr Baker: It is impossible for us to say because so much of the evidence which we receive is anecdotal. The only areas of abuse that we come across are the ones where there is evidence that is actually brought to the lawyers. To say that the general authority will increase abuse, we cannot say for certain.

Q618 Baroness McIntosh of Hudnall: Well, can I put it to you slightly differently then because I think this perhaps is an issue that we should draw out a little bit. You have said in various ways this afternoon that you feel that the Bill is insufficiently protective of the rights of those who are being cared for whilst creating a general authority for those doing the caring. Would it be fair to say that if there were a balance between the general authority, on the one hand, and some protocol that increased the protection, on the other, that, firstly, you would welcome that and, secondly, that it would at least not increase the risk of abuse insofar as you can assess that risk?

Mr Baker: It would be difficult to see how it would increase the risk if the fraudulent abuse has already taken place. If there are safeguards in place to effectively counter that abuse for general authorities, in essence, it has got to be a good thing because it means that those may be coming to the actual attention of other people to be able to be dealt with, whereas at the moment the problem we have is that nobody has any idea of what abuse is taking place.

It is all anecdotal. The Master of the Court of Protection will say, "We have no idea how many powers of attorney are even out there". With regard to the general authority, the problem I do have, however, is how will we know when somebody is acting under a general authority? We have no idea and there is no way of collating that information together.

Mr Clements: I think we do agree with what you were saying, that if there are these counterbalancing protections, then we think that the general authority would be a good thing and would not lead to further abuse and would apply to six million carers in the UK.

Chairman: Perhaps we can move on to Question 9.

Q619 Jim Dowd: Having spent quite a time going over "reasonable" and whatever that means, we come to another equally contentious word which is "appropriate". Is it appropriate for a non-medically qualified attorney to override the professional clinical judgment about medical treatment for the person on whose behalf they exercise that attorney or should they just be consulted by the clinician?

Mr Raymond: At the risk of giving what has been classed as a standard lawyer's answer, I would say sometimes yes. It is possible that the attorney will be sufficiently close to the patient to know of the patient's wishes rather better than the health professional. The problem with leaving such matters entirely with the healthcare professionals is that some of them do not necessarily look at what the patient wants, but they look at what they think is best and they do not necessarily take account of the patient sufficiently. I am trying to keep away from advance directives and things like that, but we are back, I think, really to the situation where the patient wants to move from their own home and I have had a number of cases of this. The doctor then says, "You've got to go into hospital", and the result of that is that there is a visit to A&E, all sorts of tests are done and in one case the patient died ten hours later after leaving home. Clearly in view of what was put on the death certificate, the patient was terminally ill and it should have been fairly clear that that was the case, but instead of taking account of what the patient wanted, which was to stay in his own home, the doctor insisted very forcefully in this particular case that the hospital visit was required and I think that sometimes the attorneys will have a better idea.

Q620 Jim Dowd: Is there a potential conflict for the same attorney dealing with both financial and medical matters and if there is, how can that be minimised?

Mr Raymond: We have discussed this and we believe that there is the potential for conflict, yes of course, but I think we are in a situation where the patient needs to have health warnings similar to those on the existing enduring powers of attorney to highlight the potential conflict and if they make the decision that they want to appoint a spouse, a partner, a child or somebody in whom they have an enormous amount of trust to be the person to make the decision and

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they are satisfied in their own mind that when they are able to make that decision the individual will not exploit the situation to their own ends, then that is the free choice that they will make at that stage.

Q621 Jim Dowd: But would the role of the attorney in medical matters be radically different from the way the close family members behave, those fortunate enough to have them, while they are undergoing serious treatment? Would that be radically different from the way they are treated currently?

Mr Raymond: It may be that the attorney would make different decisions from the close family members because the attorney would be the person, if we are talking about the attorney dealing with healthcare matters, in whom the donor has the most trust, the most faith that they would carry out the wishes.

Q622 Chairman: Is it the case at the moment that if you get an enduring power of attorney, that is much better than having a protection order because it is easy to get, it is more flexible and the protection order requires a statement of assets? Would that still be the case with the lasting power of attorney as in this Bill? Would that be a better option if you can achieve it than a protection order?

Mr Baker: It is all to do with capacity because the Court of Protection receivership order would not actually be put in place unless the person had lost capacity.

Q623 Chairman: Exactly.

Mr Baker: But they could not enter into an enduring power of attorney unless they had the capacity to enter into it.

Q624 Chairman: Sure, but there are cases of course of dementia where at an early stage you could get an enduring power of attorney when later it becomes a Protection Order in the case of the Court of Protection. Now, if you did that, would you then have to go for a lasting power of attorney or a protection order as the dementia got worse?

Mr Baker: No, that is not my understanding of how it would work. It would work as a registered and enduring power of attorney.

Q625 Baroness Knight of Collingtree: Is it not the case now that this particular point put to you by Mr Dowd that non-medically qualified attorneys can override a professional clinical judgment about medical treatment be rather complicated by the fact that the medical profession themselves now call providing food and/or liquid medical treatment? Has that not made it rather more difficult?

Mr Clements: We tend to fall silent when the issue comes back to advance directives and rights to life. I think it has been complicated by that decision and I think we would agree.

Q626 Baroness Knight of Collingtree: Because there is no force of law about that. It is just something that the doctors have decided at this time, is it not?

Mr Clements: It is something that has been questioned in certain human rights circles, yes.

Q627 Chairman: Are you saying that the Law Society agree with the BMA on their reading of this?

Mr Clements: No, I am saying that I probably should have kept quiet! It is a very difficult area and what I am saying is what I think is echoing what has been said, which is that the BMA statement on that has attracted some questions in certain human rights circles.

Q628 Chairman: Would you not express a view as the Law Society?

Mr Clements: Not as the Law Society, no. The Law Society has no view.

Laura Moffatt: I am just slightly worried about the concept of just feeding and giving someone fluids being treated as a treatment when in fact of course it is the method by which that fluid or nutrition is administered which is the part which they consider the treatment, and it is very invasive, either a gastrocolotomy or a tube into a vein, so that is it, not the administration of fluid or food and I think we need to be very clear about that.

Q629 Baroness Knight of Collingtree: The fact is I did want to make this very clear for the record, that it is not a question merely of the artificial giving of food which is called medical treatment, but it is everything now to do with giving food, and that is a serious matter. Would the draft Bill be actually improved by the inclusion of an explicit definition of "basic care" and that definition, provided you feel that that should happen, what should it encompass?

Mr Clements: We do not think that the Bill would be improved by a further clarification of that.

Baroness Knight of Collingtree: So there is no need to answer the second one.

Chairman: We can move on.

Q630 Baroness Fookes: Court-appointed deputies are given considerable powers under the Bill. Are you happy that there are sufficient checks upon those powers?

Mr Baker: This is a question which falls to me because this is what I do all the time, I am a professional receiver. I think there are sufficient checks because the court has an absolute power to effectively order deputies to provide records at any stage. In relation to the financial aspects, there is also the provision for security which, as you will be well aware, bites for monies to be paid back immediately into a patient's estate should there be any difficulties whatsoever. What I am unclear about at this stage is how it will work in terms of any welfare decisions in terms of the checks and how that is being taken forward. I have to say at this stage that without having more examples of how this will work, it is very, very difficult for us to give you an accurate response to that because we are not sure how the court will check upon these decisions and we would envisage that in a lot of cases most of the decisions

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may be made on a one-off basis by going back to the court for an actual definition of what they want the deputy to do.

Q631 Baroness Fookes: Is this something where you will give it further consideration for our benefit or not—

Mr Baker: I can certainly try, but it is a very difficult area.

Q632 Baroness Fookes:—or how you might see it work?

Mr Baker: I am certainly prepared to do that.

Q633 Baroness Fookes: I think that might be more helpful if we could have in mind what you think would be helpful. Could I then turn to the question of the Court of Protection itself in its new format under the Bill. Will those who have mental incapacity be able to access it sufficiently?

Mr Baker: Well, there are two aspects to the access. There is the access of actually physically being able to get to court and also the accessibility of being able to have access to justice. In terms of the accessibility to court, it was a rather retrograde step moving the Court of Protection to Archway where it is impossible virtually to get into the building and the suggestion that they make arrangements for the Court of Protection to sit around the country I am intrigued with, but I think there is an importance that we do not dilute the expertise which is within the Court of Protection and the skills which the judges and officers have. When you talk to other people in other jurisdictions, they are most impressed that the Court of Protection have all the mental incapacity dealings with finance under one roof. Naturally, if this Bill is taken forward, we will have more incapacity dealings under one roof and I think what we have got to be looking at is a better system for people to be able to actually have physical access to the court. At the moment the court sits in Preston and in London, but there is no reason whatsoever why video-conferencing should not be used more from whatever court, magistrates' court or whatever obviously provided it is in place. The other thing which is quite feasible is that there is no reason why in certain circumstances the court should not sit elsewhere other than a court building. We have actually had a hearing in our own office in Sheffield where the Master has come up and it was a sensible thing to do because it is very important that the patient has their points of view put across, so I think this is something which I do not perceive will be a difficulty, provided people are able to work with it.

Q634 Baroness Fookes: Some of our previous witnesses have been very keen on the development of advocacy. Have you any views on that?

Mr Baker: This is the second point of the accessibility and this is something which my colleague Luke Clements knows far more about than I do.

Mr Clements: It is all very well to talk about courts which are accessible or which have sound loops or have lifts, but for every one person with mental

capacity difficulties to get to court, there are probably 100,000 who have no access because the mere concept of stepping into a solicitor's office is intimidating, as it is for all of us, and the reality is that people with mental capacity difficulties never take the first step. There have really only been about four cases in the European Court of Human Rights on this issue of the tens of thousands of cases they have looked at. It shows that people with mental capacity problems do not have access at the very first stage. We see the issue of advocacy as utterly fundamental. I have already spoken about the fact that to take instructions from somebody with capacity difficulties may take hours and hours and hours and the Legal Aid Board or whatever it is called now, the Legal Services Commission, is not going to pay me a high rate to do that, so people with capacity difficulties have got to have advocates who will enable them to access this. There may be financial problems with that, but the Government, in its legislation, has effectively created an obligation to have national advocacy. In the *Valuing People* White Paper it said that that it would be a core service that every local authority should serve people with learning disabilities. In the Older People's National Standards, the idea is to develop older people's advocacy rights. The Mental Health Bill will create a statutory right, if it emerges in the same form, to advocacy. In children's proceedings there is now a minimum for advocacy and of course we now have the Patient Advocacy Liaison Service which has been run by the CABs in large measure throughout the country providing an advocacy service through the NHS process, so we have at least five separate developments of advocacy and we would say that that is actually fundamental to enabling people with capacity difficulties to access to justice.

Q635 Baroness Fookes: This of course could be very expensive. I may now be being cynical, but government is often the ends, but not the means.

Mr Clements: Well, Parliament wills both of these things hopefully.

Q636 Chairman: It does not always work like that!

Mr Clements: I think the point we are saying is that the apparatus for advocacy is already there. I think the implications of Article 6 of the European Convention and now the Human Rights Act are that there will have to be advocacy. Article 6 says that you must have access to justice and the court has said in certain cases that that could be legal aid, but we would say that much more fundamentally serious than to have legal aid, although lawyers would benefit from that, is to have advocacy. Advocacy exists throughout the country, it is a growing movement and there are, as I said, at least five government initiatives on this and the Government has put some significant money into some aspects of it, I think some £3.5 million into it in *Valuing People*.

Q637 Baroness McIntosh of Hudnall: This does flow from the discussion we were just having. You said in your written submission that you were puzzled

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about the way that the lasting powers of attorney provisions were set up there is the issue about jointly and severally and the potential for there to be two or even three or more attorneys, but you have said very clearly that this would be subject to there being adequate provision to resolving disputes. I can imagine circumstances in which disputes between people with power of attorney, particularly family members, one might say, might be quite hard to resolve. Do you have a sense of what would be the appropriate or indeed adequate arrangements for dispute resolution in that sort of area, particularly informal mechanisms rather than those that ultimately wind up in the courts and can you talk a little about how your obviously very fervent belief in advocacy as part of this overall process fits into that because, on the face of it, it looks as if there might be a role for an advocacy procedure in resolving disputes of that kind?

Mr Clements: Perhaps I can deal with the very simple bit rather than the complex issue of lasting powers of attorney and more than one appointee. I am not suggesting that advocacy is the cure, particularly where you are dealing with two people who have capacity who are arguing about who is in a position to make decisions dealing with an incapacitated person. I am not sure advocacy would be for them, but there are community mediation schemes. I think, in relation to housing disputes, anti-social behaviour and those sorts of things which are being developed by local authorities and there are mechanisms which could perhaps deal with that.

Q638 Baroness McIntosh of Hudnall: So you are saying that there are models for conflict resolution which could be easily moved into this area?

Mr Clements: Yes.

Q639 Baroness McIntosh of Hudnall: But in some circumstances—

Mr Clements: I think as the public law, administrative law system has grown enormously and the judicial reviews have grown beyond expectations, we are now all looking for alternative dispute mechanisms and the court itself has been quite strong on that. We warmly welcome solving things locally and as soon as possible and there are models, although we cannot say in this situation that there is this solution, whereas we think with advocacy there probably is with the problems that learning disabled people have.

Q640 Baroness McIntosh of Hudnall: So you would expect to see an appropriate model in a code of practice underpinning the legislation?

Mr Clements: Yes.

Q641 Baroness McIntosh of Hudnall: You said you felt that the question about more than one person with lasting power was more complex. Can you just unpack that a bit?

Mr Clements: All I can say is that in preparing this, we had quite a large group of lawyers and the one who was very strong on this point is not present. I

did not understand the point, but I am not an expert. It is something that we might deal with in written submissions.

Q642 Baroness Barker: This question is about the advocacy service and the status of them. I am professionally a very big fan of the advocacy service, but I wonder how it is possible to ensure that an advocacy service is not a sort of second-class service. I would like you, perhaps not now, to address for me what happens when a client has an advocate and it is a community care financing case and they are put against the local authority solicitor. What happens then? Also if you were to write to the Committee, I would like you to say a bit about the distinction between lawyers who are bound by client confidentiality and the advocacy role.

Mr Clements: I have written a very good book on the subject and I also run a postgraduate programme in Warwick dealing with this particular issue because there is no simple solution. I think what one has to remember is that confidentiality is not an absolute—it is an issue which can yield in certain situations (basically a qualified right) and although the presumption is in favour of confidentiality, it has to give way at certain stages. It is a hugely complicated issue in a fairly fast-moving area because of the Human Rights Act. I am very happy to send you a copy of my book!

Q643 Chairman: We touched on this earlier, the question of public law protection. The Law Society suggest that the Draft Bill should impose duties on local authorities and the NHS to investigate the cases of suspected abuse of adults who lack capacity. They further suggest that a Mental Health Commission should be created to oversee the Public Guardianship Office and the local authorities. If we were not persuaded to recommend that such measures should be introduced how seriously do you think the value of the Bill would be impaired?

Mr Clements: We really strongly welcome this Bill. We would want this Bill to go forward. We give it all encouragement possible. We regret strongly that there is not a public protection provision in it. We are of the opinion that inevitably legislation would have to be brought in to deal with this. The High Court is now taking control of this and High Court proceedings are expensive. Although we believe the Bill would be less effective it would still be an extraordinary achievement.

Q644 Chairman: Moving on to public funding for legal advice and representation, how do you suggest that the new Court of Protection can be made accessible to people with limited financial means in the context of increasing and competing demands on the legal aid budget? Finally, an easy question: is there any way of estimating the costs of all this?

Mr Clements: The only idea we had on costs was to see what Scotland was spending on this matter and multiply it by whatever the appropriate figure should be. As I understand it, this Act has created no major case in Scottish courts so it has not been a

15 October 2003 Ms Vicki Chapman, Mr Peter Raymond, Mr Niall Baker and Mr Luke Clements

“nice little earner” for lawyers, unfortunately, and therefore it may well be that the cost impact is not as much as one might have feared.

Q645 Chairman: If colleagues have no further questions, can I thank you very much for a very helpful session.

Ms Chapman: Thank you very much for inviting us.

29. Supplementary memorandum from the Law Society (MIB 1194)

There are three points the Law Society would like to make, all of which concern financial matters. The first two are about missed opportunities, while the third point identifies unnecessary bureaucracy created by the Bill.

1. The objective of this Bill is to introduce new mechanisms to allow certain decisions to be made. However the opportunity to consolidate the law relating to Powers of Attorney has been missed. Currently as proposed under the Bill there will be four principal types:

- A pre-existing Enduring Power of Attorney under the 1985 Act.
- Lasting Power of Attorney under the new Act.
- Ordinary Power of Attorney under the 1971 Act.
- Trustee Power of Attorney under the 1971 Act (valid only for 12 months).

The Law Society recommends that the 1971 Act is repealed and the powers described above dealt with under the new Act, within the instrument which also vests Lasting Powers of Attorney.

2. The Law Commission in its report (No 231) highlighted its concerns about the appointeeship process—the process whereby a substitute is appointed by the Secretary of State to receive social security benefits on behalf of an incapacitated adult. Problems with this process were also raised by the Parliamentary Ombudsman in her report of 8 July 2003.

The Law Society considers that that the absence of any adequate appeal provisions for individuals subject to appointeeship is unsatisfactory. Presently an individual who wishes to challenge the appointment can merely request that the Secretary of State exercise their discretion to revoke the order. In our view this is contrary to natural justice and infringes the individual’s human rights under Article 6(1). We would suggest that an alternative remedy would be to enable the individual under this Act to have a right of access to an Appeals Tribunal.

3. Under Schedule 4, Receivers appointed by the Court of Protection prior to implementation of the Act will be accountable to the Public Trustee. The Public Trustee is then accountable as a deputy to the Public Guardian. The Law Society is not convinced that this additional layer of bureaucracy will enhance any purported protection; it is more likely however, that it will cause unnecessary delays.

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30. Further supplementary memorandum from the Law Society (MIB 1212)

HUMAN RIGHTS CONCERNS

Appointeeships

As we detailed in our supplemental note, the inability of persons who are the subject of an appointeeship order, to challenge this before an independent tribunal raises issues under article 6(1)—given that an interference with a person’s social security benefits amounts (in certain cases) to an interference with a civil right for the purposes of article 6(1). We recommend that the legislation be amended to enable access to the Appeals Tribunal in appropriate cases to determine such disputes.

Clause 7

This authorises detention in certain situations. The clause as currently drafted does not require that the situation be an emergency (or one of “urgency”) or that the period of detention be for as short a time as possible (or be the “least restrictive” possible). Article 5 will be engaged if the detaining person is an agent of the state—and the clause is problematical since it lays down no “procedure” as required by article 5(1).

If the detaining person is not a public authority (for instance a private care home) then the detention could arguably constitute degrading treatment—and needs to be regulated by law (the European Court of Human Rights’ jurisprudence holds states responsible for deficiencies in their domestic law when fundamental rights (such as the right not to be subjected to abuse) are at stake—*A v. UK* (1998; 27 E.H.R.R. 611; *X & Y v. Netherlands* (1985; 8 E.H.R.R. 235).

The new Court of Protection

We are concerned that legal aid (public funding) is not available for proceedings in the present Court of Protection and it needs to be made clear that this restriction will be removed in relation to the new Court. Given the width of jurisdiction of the new Court—the principles established in *Airey v. Ireland* (1979; 2 E.H.R.R. 305) requires that legal aid be available in appropriate cases. It is also arguable that the requirement that a “litigation friend” give the court a personal undertaking to be responsible for the costs of the proceedings, constitutes an unreasonable restriction of access and/or disproportionately discrimination in relation to the article 6(1) right—and this should be reviewed¹.

The general authority

The width of the general authority, the absence of any potential limits on its scope (ie financial maxima), the lack of adequate mechanisms for redressing abuse, and the absence of any objective requirement of reasonableness for the use of the power (ie it is based upon a subjective belief of reasonableness by the person exercising the authority) raise concerns as to whether the general authority provides sufficient respect for the vulnerable persons’ possessions (ie its compliance with article 1 of the first protocol read in the context of the UK’s undertaking under article 1 of the Convention).

Luke Clements

October 2003

31. Further supplementary memorandum from the Law Society (MIB 1215)

1. At 1.2 of our submission we take the view that the Bill does not clearly distinguish between persons who acquire mental impairment from those whose impairment has always been present. As stated in the oral evidence, this was an inelegant example and it is one which is best addressed through the use of the general principles in the place of best interests as proposed under the current Draft Bill.

2. This point was raised to differentiate between facilitating and encouraging self advocacy from that of substituted decision-making. In our view, the way the Bill is set out, these two solutions are not adequately emphasised and in our view this has caused many organisations promoting the rights of learning disabled people to take the view that their rights are being taken away. Our understanding is that the Bill is not intending to do this and the way in which the general principles are set out may assist the Committee in making their recommendations. It is worth noting that the Scottish Bill was strongly supported by many learning disability groups and was not the subject of criticism in quite the same way as the current draft bill.

HUMAN RIGHTS INCOMPATIBILITY

3. Details have been sent to supplement our evidence in this regard separately.

REASONABLENESS

4. A member of the Joint Committee took the view that the question of reasonableness is always an objective test. There is much case law on the issue of reasonableness and whether this is an objective or a subjective test and in the view of the Law Society it would be bad law to legislate using terminology which may increase the likelihood of future litigation. For this reason the Law Society takes the view that whether the reasonableness here is an objective or a subjective test should be made clear on the face of the Bill.

5. The suggested text by the Law Society mirrors that contained in the Disability Discrimination Act 1995.

CHECKS AND BALANCES OF DEPUTIES

6. The Law Society agrees that a checklist would be of some assistance in maintaining a standard for court appointed deputies. However, the content of this list is a matter that warrants careful consideration and our suggestions should not therefore be read as exhaustive.

7. We are of the view that, in relation to financial matters, there should be a requirement to provide written financial information subject to a de minimus rule, for example of an estate under £5,000. There should be a requirement to seek the approval of the court in any matter that may have significant effects, either on the financial estate or on the care of the person, for example a change of residence or primary carer. There should be a duty to report concerns such as suspected neglect or abuse of primary carers. The code of practice may be a suitable vehicle for further details and examples to illustrate its application. The Law Society would wish to reiterate that we believe deputies should be subject to a code of practice in as much the same way as attorneys.

¹ Rule 21.4.3.c, Civil Procedure Rules.

MEDIATION

8. The Law Society have promoted the use of mediation as a mechanism to assist carers, persons under the Bill and professional bodies in the resolution of disputes for which a formal court setting may not be proportionate. Some would argue that mediation in principle sounds like a generally good thing but in practice is expensive and does not resolve disputes, especially in the case of litigious persons. The Law Society would question this, although obviously there are litigious persons and any amount of mediation will not prevent them wanting their day in court.

9. By way of background, mediation was introduced in the Family Law Act 1996 and pilot schemes were researched and evaluated extensively. It is agreed that aspects of this provision were problematic; in particular the fixing of timing at an early stage of a divorce, and the limiting of compulsory consideration of mediation to publicly funded clients. Many of these proposals have since been mitigated and at a core level of family mediation work is now firmly established within family proceedings in England and Wales. Contrary to popular belief mediation has proved effective in children disputes, especially those relating to contact. The Law Society takes the view that there is a parallel in children disputes in the case of persons who have mental incapacity. Disputes may often be between different family members and may need input from social services. Mediation is also widely used in finance disputes. There are other small-scale pilots which have been available on other types of ADR schemes.

10. Last year approximately 13,000 publicly funded family mediations were conducted in England and Wales and a significant number of disputes were settled as a result of family mediation. Added to this there are disputes that may not have settled immediately but were resolved relatively quickly as a result of the family mediation. Even in cases where parties do go on to litigate, the use of mediation often helps to clarify and narrow the issues for the litigation process. Again a parallel can be seen in how this would assist the work of the Court of Protection. It brings a wider benefit by making the court process more efficient. The Department of Constitutional Affairs is currently looking at wider spread initiatives to increase the use of ADR in other family proceedings. The Law Society would suggest that this should also apply to persons affected by the incapacity legislation.

11. As stated in our oral evidence there are many community mediation projects which are up-and-running. For example, disputes which are often acrimonious, expensive and drawn-out can be resolved highly effectively through the skilful deployment of mediation. A number of local authorities have set up or expressed an interest in mediation schemes to resolve neighbourhood disputes. This has also been extended to other forms of disputes such as anti-social behaviour. Although a direct parallel cannot be made in the current legislative proposals, it does however represent a network of mediation projects which is already up-and-running nation-wide on which the DCA may wish to build.

12. Perhaps the time has come for mediation to be nationally accredited and professionalised in much the same way as the service of advocacy schemes.

ASSESSMENT OF CAPACITY

13. In the Law Society's opening paragraphs of the submissions to the Joint Committee, we stated that much of the detail on which we comment may be intended to be included in the code of practice. The Law Society would like to take this opportunity to reiterate that on the assessment of capacity, the BMA and the Law Society has some excellent guidance which is freely available. An updated version is shortly to be published. We would consider that this would be an excellent base on which to build a code of practice in this area.

CONCLUSION

14. The Law Society very much welcomes the pre-legislative scrutiny process as a constructive forum where issues can be well thought out, researched and discussed in advance of final drafting. It is particularly conducive to committee style organisations where separate interest groups feed into a larger body. This includes alliances such as the Mental Health Alliance and the Making Decisions Alliance. The Law Society would like to take this opportunity of thanking the Joint Committee for their part in this process and we hope that the information we have supplied will be of some assistance to you.

October 2003

Tuesday 21 October 2003

Members present:

Barker, B.	Mr John Bercow
Carter, L. (Chairman)	Mrs Angela Browning
Fookes, B.	Stephen Hesford
Knight of Collingtree, B.	Mrs Joan Humble
McIntosh of Hudnall, B.	Huw Irranca-Davies
Pearson of Rannoch, L.	Laura Moffat
Rix, L.	

32. Memorandum from Changing Perspectives (MIB 71)

MENTAL INCAPACITY BILL

This Bill should start from the position that a person can make decisions and that appropriate support is in place. There must be recognition that some people can't make decisions if their communication needs aren't met, whether through provision of interpreters, communication facilitation or appropriate equipment or their behaviour/gestures have not been correctly interpreted alongside inaccessible information. There is nothing in the bill which will make it law for such support to be provided so that the person without perceived capacity can be involved in the decision making process.

Additionally, there is no provision of advocacy. This is an obvious gap in this proposed legislation and the Disabled Peoples and Representation Act 1986. It is critical that any proposed legislation must include such proposals as one person says:

"My carer is trying to stop me getting my own house, if it wasn't for help from my advocate I would not be moving."

Without such proposals many people may be **WRONGLY** perceived to be without capacity, when in fact they need support on how to participate in the decision-making process.

The Mental Incapacity Bill assumes that anyone making decisions on behalf of people without perceived capacity is always acting in their best interests. There is no acknowledgement of any conflict of interest, which may rise in any decision, both "significant" and "insignificant". Some examples where the bill may allow others to make decisions on behalf of people without perceived capacity where conflict of interests will arise **WITHOUT FAIL**.

John and Lesley were living in separate group homes. Both of them were married and wanted to live together as a couple in their own home with support of Direct Payments. The staff in the group homes were against the idea and made this clear at John's care planning review meeting.

The conflict of interest arises where the staff are only being paid whilst residents live in the home. It is not in the staffs' interests if residents want to live on their own.

Another example will be where persons without perceived capacity are living at home.

"I did not have control over my money at all. When I asked for money I only got £5. If I spent it she got mad."

This is another example where there will be conflict of interest. In this case, parents may rely on the financial income from their daughter or son with learning difficulties and therefore be unwilling to give money to him or her.

We have concerns that the Mental Incapacity Bill will violate the fundamental rights of people without perceived capacity. Under Article 6, the claimant must have a right to an effective remedy where his/her European Convention Of Human Rights (ECHR) have been violated. The proposed Bill **GIVES NO EFFECTIVE** Remedy if a person without perceived capacity believes his/her fundamental rights (ECHR) have been violated. In this case Articles 6, 8, 10, 14 (the right to a fair trial, right to privacy and family life, freedom of association and assembly and not to be discriminated against on the grounds of disability.

Such cases where people without perceived capacity rights will be violated:

This Bill will affect the rights of people without perceived capacity, in this case disabled people labelled with learning difficulties.

"I don't like people (staff) interfering with my choices. I would like to go where I want when I want . . . Staff have stopped me from washing up." (ECHR article 8 violation.)

"I am not allowed to take my own medicine; the staff say I can't manage it, even though I coped with it well in both group homes I have lived in." (ECHR article 8.)

"Julie and I planned to get married, the staff at Julie's group home stopped us from seeing each other and have sent Julie's engagement ring back to me." (ECHR article 8 violation.)

"My daycentre staff will not let me go to my local People First office and try to stop me going to conferences and other events," (ECHR article 10 violation).

If the Mental Incapacity Bill becomes law Disabled People with learning difficulties like these would have no RIGHT to appeal where a declaration that their rights have been violated. Furthermore, the person with learning difficulties will not be able to seek an injunction against the decision makers.

It is very clear that the Human Rights Act covers the actions and decision-making processes of statutory bodies. This also includes service provision. Such landmark cases include X, Y and Z where it was ruled that the manual handling procedures of carers/personal assistants services must respect disabled care recipients with learning difficulties fundamental human rights (Articles 3 and 8). The Human Rights Act is limited to STATUTORY Bodies decisions which may include their directly contracted services. The Human Rights Act is likely to fail when non statutory bodies or persons employed by them make decisions on behalf of persons without perceived capacity. Many people with learning difficulties are stopped from making and implementing their own decisions by their parents and carers who would not be covered by the Human Rights Act.

"I do a lot of volunteer work for People First which means I travel all over the country. I have to keep my trips around the country secret from my Mum, I am sure she will try to stop me if she finds out."

"I am stopped from going out by my Mum, I would like a place of my own because sometimes I am treated like a child, and I wish I could do things myself."

When such decisions are made on behalf of persons with learning difficulties there will be no redress even under the Human Rights Act. Such redress will need to be incorporated in any proposed Bill.

The Government says there is sufficient checks and balances to ensure that only the right people can make decisions on behalf of someone without perceived capacity. From our understanding a person can make decisions on behalf of another if she or he "reasonably" believes that a person lacks capacity to make a particular decision. The problem with this is that it allows anyone to consider another can't make decisions based on the stereotypical assumptions about what people with learning difficulties can do as People First say.

"People without learning difficulties often only think about what they think we can't do, rather than what we can do, or could learn to do."

The Government says that some decisions should be made by the courts. Here, the Bill have not specified which decisions should or should not be made by the courts. As a consequence it will be left up to the "integrity" of the decision maker to invite the courts to make a ruling. We would assume that most decision makers wouldn't refer the matter to the courts. As with now, the courts are involved with financial and healthcare matters for people without perceived capacity where one would expect legal safeguards to be in place. However, it is unclear whether such legal safeguards will remain.

Where a person is unable to make a decision for whatever reason legal safeguards must be in place to ensure ALL decisions are made in the best interests of the person with perceived incapacity. Anyone making decisions must be registered. Independent advocates must also be involved.

We think having a lasting power of attorney is a good idea where people who are unable to make decisions can choose people who they can trust to make decisions for them. This could be extended to selecting particular persons to make specific decisions.

To conclude we would like to see a Bill titled "Supported Decision Making" where the focus will be on how people can be supported to make their decisions. Where decisions cannot be made by a person a tough legal framework is in place to ensure conflict of interests of decision makers is kept to a minimum.

Changing Perspectives providing training and consultancy on disability rights issues. Simone Aspis (director) and disability rights activist was the former People First Parliamentary and Campaigns Worker. Additionally, Simone has been very active in campaigns to safeguard the rights of disabled people who are perceived to be without capacity.

Alongside People First, we would be interested in submitting oral evidence. It is important that the committee hears the voices from many disabled people with learning difficulties. The Committee needs to find a balance of hearing non disabled people's organisations that claim to represent people with learning difficulties and self-advocacy groups run by disabled people with learning difficulties.

33. Memorandum from People First (MIB 778)

Dear members of the Draft Mental Incapacity Bill Scrutiny Committee.

Here are People First's views on the draft Mental Incapacity Bill.

People First is a national umbrella organisation for over 100 self-advocacy groups of people with learning difficulties.

People First members think the Government's ideas in the draft Mental Incapacity Bill will mean that people with learning difficulties will be bossed about and controlled even more than we are already. (There is a list of things People First members have said about control in their lives at the end of this letter)

We think this law is more about people making choices for us, than about our rights to make choices for ourselves.

The Government says that it wants a new mental incapacity law to make sure people are allowed to make their own choices, but we think the main reason for bringing out the new law is because of pressure from parents, and carers, organisations and from service providers, so that carers and paid staff will be legally covered if they make choices for someone with learning difficulties.

The Mental Incapacity Bill could result in people without learning difficulties over-controlling people with learning difficulties.

The decisions should be made by us it is important that we don't go back to the old days where disabled people were not allowed to live independently.

People First do not like this Bill because it will take away our independence and break our human rights it will also go against the Government white paper, Valuing People.

People will be able to read between the lines and pick bits out of the new law to boss us about.

The Government's proposal to give a "general authority" to anybody to make decisions for someone who they think is unable to make their own decisions is especially worrying. This will mean that anybody will be able to legally interfere with a person with learning difficulties' life as long as they think what they are doing is the best thing for the person with learning difficulties.

We think it is very dangerous to give a right to people to make choices for another person on the basis that they "believe" the person is incapable of making their own choices.

How are people going to make a decision on who can and cannot make decisions? Where do you draw the line? Someone may say yes I can make my own decisions and another may say no I cannot make my own decisions.

Lots of People First members have relatives or paid carers who always assume that we cannot make choices for ourselves just because we have learning difficulties.

Relatives and paid carers often think that we are not able to do things that we can do, or could do, given the right support. They often overprotect us and will not let us do anything that they think is at all risky.

There is no guarantee that everyone will just help people the way they are supposed to, because some people only see us as children, not what we can do and how we can do things for ourselves, they will only say no you cannot do that because they only like to be seen to have the power over us, which is wrong.

Also, people have the right to make "bad" decisions. This Bill would mean workers and carers having too much power, this is wrong.

People without learning difficulties often do not let us make choices for ourselves, because they cannot be bothered to spend the time and effort to help us make a choice for ourselves. People need time to make decisions. The draft Mental Incapacity Bill says nothing about how the Government will make sure that we are given enough time to make choices for ourselves.

The Mental Incapacity Bill says lots about how you should help someone make their own choices. It also says lots about how to make a decision for someone which is in their best interests, but this is no good because there is no way of checking that somebody has really tried to help someone make a decision for themselves, or that a decision has really been made in someone's best interests.

The draft Bill says nothing about how the government will make sure that people are really supported to make choices for themselves.

Our relatives and paid carers and other people often say we cannot make a choice ourselves because they don't like the choice we want to make for ourselves.

Don't you think it's wrong for any person to make a decision, like for example a next door neighbour does not like people with learning difficulties, so the neighbour says that she or he doesn't think that she or he can live independently and make their own choice if they want to go shopping or pay their own rent.

Relatives and paid carers often stop us from making our own choice because they want us to make a choice which is best for them, rather than what we want. Many People First members have had people like relatives, carers and social workers who have made decisions for them which have been best for the relative, carer or social worker, not for them.

The draft Bill says nothing about how the Government will make sure that choices are being made for people with learning difficulties that are best for them rather than best for their relatives or carers. The Government is putting too much faith in our carers, relatives and other people without learning difficulties to make decisions for us that are really in our best interests.

There are often conflicts of interest between us and our relatives and care workers, the draft Mental Incapacity Bill does not take proper account of this.

An example of this is where a person with learning difficulties wants to move out of their parents' home into their own flat. The parents say that their daughter or son is unable to make this decision, but their real reason for not allowing their son or access to their son's or daughter's social security benefits, or lose the extra pension they will get if their son or daughter is still living with them when they reach retirement age.

Another example is where a person says that they want to get direct payments to organise their own care, instead of living in a residential home or going to a day centre. The staff in services like this may say that someone is not able to make this choice, but the real reason they are saying that someone is incapable of making this choice, is because the staff working in the service are worried about losing funding attached to the person and therefore, the possibility of losing their jobs.

We think it is very bad that people who are bossing us about to suit themselves will be able to say "we thought it was the best thing for them", to defend their actions if they are challenged. It is too easy to just say "I thought they were unable to make the choice and I did what I thought was best for them"; there is no way of disproving this.

Another very big problem with the Mental Incapacity Bill is there is no way for people with learning difficulties to challenge decisions that have been made for them.

People First asked Rosie Winterton MP, (who was the Minister responsible for the Mental Incapacity Bill before Lord Filkin), how somebody will be able to complain if they are being stopped from making choices which they think they should be allowed to make. The Minister's answer was "we just don't know."

People First thinks that it is really bad to give a right to people without learning difficulties to make choices for us, without giving us a way to complain if we disagree with choices being made for us.

The draft Bill says nothing about easy ways for people to complain if they disagree with choices that are being made for them, or if they disagree that they are incapable of making their own decision(s).

It will be very, very hard for people to complain to the Court of Protection, especially if they have no independent support, like an advocate, to do this.

It will be very hard for people who have communication difficulties to complain and these people are even more likely to be labelled as incapable of making their own decision(s). If workers, carers etc, don't communicate in ways the person needs, they are likely to say the person can't decide for themselves.

People who have labels like "profound learning difficulties" are the people who are most likely to be labelled as not able to make their own decision(s), but it is these people who are usually most isolated and have no one to support them if they want to challenge decisions that are being made for them.

The draft Bill does not give people who are having choices made for them a right to an independent advocate. If the government were really serious about making sure people who find it hard to make choices were in control of their lives, they would be making a law giving us a right to independent advocacy.

If the draft Mental Incapacity Bill becomes law it will be a very big step backwards for people with learning difficulties' rights.

Annex

Here are some things People First members have said about paid carers and relatives controlling their lives. These stories show that giving more power to our relatives and paid carers to make decisions for us is a very bad idea which would lead to our lives being controlled even more.

"We have no access to our money, we are treated like children and patronised by staff."

"I have to go to bed at nine o'clock, get up at seven o'clock and have a bath straight away, just because the staff say so, not because I want to."

"I was not allowed to make a cup of tea myself at my family placement. People First helped me make a complaint. Now I can make a cup of tea when I want to."

"I do a lot of volunteer work for People First which means I travel all over the country, I have to keep my trips around the country secret from my Mum, I am sure she will try to stop me if she finds out."

"Julie and I planned to get married, the staff at Julie's group home stopped us from seeing each other and have sent Julie's engagement ring back to me."

"I was told for years by my residential home staff that I was being stupid to think I could live more independently. Now I live in my own flat and have got married."

"I am not allowed to take my own medicine; the staff say I can't manage it, even though I coped with it well in other group homes I have lived in."

"I was told I must tidy up my room when the staff tell me to, otherwise I will be sent back to the long stay hospital."

"My fiancé and I have been told that she can only stay at my group home on one day each weekend because of insurance requirements."

"The group home where my partner lives will not allow couples to sleep in the same room if they are not engaged or married."

"I have a problem with my parents and he always shouts at me, he always drinks too much at home and I get upset. I would get a flat of my own but my parents say I can't get my own flat."

"I don't like people interfering with my choices, I would like to do what I want when I want. I don't want to be ignored because I can't hear very well. Staff have stopped me from washing up. I wish I had more choices than watching the television at home. I would like to live on my own with a carer."

"My carer is trying to stop me getting my own house; if it wasn't for help from my advocate I would not be moving."

"I want to look after my own money."

"I don't like being told what to do. I don't like being told when to change my trousers or to go to bed."

"I want to work but staff in my home stop me."

"I am stopped from going out by my Mum, I would like a place of my own because sometimes I am treated like a child. I wish I could do things myself."

"Staff at the adult training centre treated us like children; they tried to stop me and my girlfriend seeing each other before she became my wife. We are married now."

"I couldn't do what I wanted to do when I lived at home. I had to be in bed by 10 o'clock. I had to be up by six o'clock to be at the centre. I didn't have control of my money at all. When I asked for money I only got £5. If I spent it she got mad."

"My daycentre staff will not let me go to my local People First office and try to stop me going to conferences and other events."

"My Mum and Dad shouted at me and my father even said he would murder me."

"I live with my father, we are both deaf, he drinks too much, he bosses me about and he has hit me."

"My Mum stopped me from seeing my girlfriend, I was so upset, I really loved her but my parents kept stopping us. When she told me I could not see my girlfriend again I went mad and went to my bedroom and slammed the door, I wanted to ring my girlfriend but my Mum wouldn't let me, I know my girlfriend phoned and asked to speak to me, but my Mum told her no."

"My community nurse tried to stop me going out to see my Mum, she made up a story to back her decision but it was false, she lied, she was sacked for it."

"Before I went to People First I wouldn't speak up for myself, now I can speak up and I control my life. Now I am getting my own flat, I will be able to make more decisions for myself."

"My Mum said I can't have a boyfriend."

"I have to go to the daycentre because my Mum says otherwise I will lose my place."

August 2003

34. Memorandum from Values into Action (MIB 733)

1. Values Into Action (VIA) has been working since 1971 to promote and support the development of good, positive policies and practices towards people with learning disabilities. We are entirely independent and promote only the interests of people with learning disabilities. We carry out our work through research and development, publications, training and conferences.

2. VIA has a long history as a leader on decision-making issues. We have researched the theory, practice and implementation of current and potential systems of supporting people to maximise their decision-making capabilities within a legal context, and have published widely on the subject (see list of publications on page 4, one of which—Making Decisions—is enclosed).

3. Over a number of years we have advised and liaised with officials at the Department for Constitutional Affairs, and are pleased that draft legislation has now been produced. However, we are dismayed that less than two months, in the height of the holiday season, was allowed for submission of written evidence to the Joint Committee. This is important legislation and every effort needs to be made to ensure that the interests and safety of the many people who will be affected by it are properly represented and protected.

4. The present draft Mental Incapacity Bill contains a number of elements which we support. We are pleased that:

- (a) the Bill recognises that people may have the capacity to make some decisions whilst they may not be able to make others (Clause 1);
- (b) all practicable steps will have to be taken to help a person make a decision before they can be judged as unable to make it (Clause 2);
- (c) there is a presumption against lack of capacity until and unless it is established that the person lacks capacity (Clause 3);
- (d) the person must be involved in the decision as far as possible, and their views and those of others in their lives taken into account (Clause 4).

5. However, VIA is extremely concerned about the nature and scope of the general authority as set out in Clauses 6 and 7. As currently proposed the general authority represents a potential threat to the safety, satisfaction and wellbeing of anyone at risk of being judged to lack capacity. In particular, its powers:

- (a) may be exercised by anyone “when providing any form of care” (Clause 6(1)) regardless of who the individual is or the nature of their relationship with the person;
- (b) may be exercised by a range of individuals acting independently with no overview or plan for the person in question;
- (c) may be exercised by a single individual over a long period of time according to their own personal view of the person’s needs and preferences;
- (d) are not subject to any form of monitoring, review or other safeguards;
- (e) are not susceptible to challenge except by appeal to the Court of Protection;
- (f) cut across the provisions noted above in Clauses 1, 2, 3 and 4, in that “reasonable” belief that someone lacks capacity will effectively nullify the intentions of Clauses 1, 2 and 3, whilst “reasonable” belief that their decision is in the person’s best interests will effectively nullify Clause 4.

6. The Government’s 2001 White Paper *Valuing People: A New Strategy for Learning Disability in the 21st Century* directs that person-centred planning be an integral part of decision-making around a person’s life. Person-centred planning requires that all decisions are reached with maximum possible input from the person, and reflect what the person would really want. To achieve this where someone’s decision-making capabilities are limited (perhaps extremely limited) requires the use of supported decision-making techniques (see the enclosed publication *Making Decisions*). It is a matter of concern that the draft Mental Incapacity Bill takes no account of either person-centred planning or supported decision-making, and sets up a separate and antithetical decision-making avenue.

7. All people with learning disabilities are able, with support, to indicate their preferences and thereby help to determine the course of their own lives. Their right to do this is enshrined in the Human Rights Act 2000 and underlined by *Valuing People*. However, because these abilities and rights are not recognised by the draft Bill many people with learning disabilities will find themselves excluded from decision-making altogether. The general authority, as it now stands, will enable other people to decide for themselves that someone lacks capacity, and then to decide for themselves what that person should do throughout the course of their life, with no oversight, no regulation and no easy system of challenge. It will be up to the person who is deemed to lack capacity to make their own complaint to the Court of Protection—a highly unlikely scenario, especially given the total absence of advocacy support in the Bill.

RECOMMENDATIONS

8. VIA believes that the draft Mental Incapacity Bill, and particularly the general authority, far from protecting vulnerable people actually substantially increases their vulnerability. We strongly recommend that the whole notion of the general authority be completely re-thought before the Bill progresses farther.

9. We further believe that the following changes to the general authority would help to reduce the potential harm to vulnerable people, including people with learning disabilities:

- (a) The general authority should cover only minor decisions. Guidance should be issued on which decisions would fall within the remit of the general authority and which would need to be referred to the Court of Protection.
- (b) The Bill should require records to be kept of all decisions made, including what the decision was, who it was made by, the reasons for it being made, how it will benefit the person and how the person was involved in it.
- (c) Decisions under the general authority should be taken jointly by at least two people, one of whom should not be a member of the person’s family or services.
- (d) Complex or difficult decisions should require the involvement of additional people.
- (e) Guidance is needed on the interpretation and prioritisation of “best interests”.
- (f) Every decision made should clearly be to the benefit of the person deemed to lack capacity.

- (g) No person acting under the general authority should benefit from any decision made.
- (h) The Bill needs to set out a process of decision-making which would incorporate the steps to be taken to ensure the fullest possible participation by the person deemed to lack capacity.
- (i) New guidance is needed on the use of supported decision-making to ensure the fullest possible involvement of the person deemed to lack capacity.
- (j) The Bill needs to state the role to be played by person-centred planning.
- (k) The Bill should provide a system for the monitoring, review and challenge of decisions taken under the general authority.
- (l) There needs to be a local, informal and easily-accessible court to facilitate decision-making, mediation and appeals.
- (m) Use of force and restraint under the general authority should not be lawful.
- (n) The Bill should provide adequate resources for advocacy services to ensure that all people at risk of being deemed to lack capacity have access to advocacy.

10. I have already informed the Assistant Clerk to the Joint Committee that we would welcome the opportunity to provide oral evidence. I now wish to confirm that we would very much like to discuss and explain further the points made in this paper.

August 2003

Witnesses: Ms Simone Aspis, Director and Mr Richard Downs, Changing Perspectives. Mr Andrew Lee, Director and Mr Nico MacGiven, Campaign Officer, People First. Dr Jean Collins, Director and Mr Mark Brookes, Values Into Action, examined.

Q645 Chairman: Good afternoon, I would like to welcome you here. I would like to thank you for your written evidence, which is very helpful, and also finding the time to come and help us this afternoon. As you know the session is open to the public, it is being recorded and broadcast and if you are interested it will be on the Parliament Channel at 6 o'clock on Sunday evening. There will be a transcript of the evidence which you will see and if you wish to correct it you will be able to do so. If there are divisions in either House I will have to adjourn for about 10 minutes while either the peers or the MPs will have to go and vote. Even though we have microphones in this room the acoustics are not particularly good, if you would speak up it would be helpful. If we are unable to reach all of the questions we sent to you in advance and you want to write to us afterwards with your views on those or any of the exchanges that we have afterwards that is entirely in order. Can I suggest that you might like to introduce yourselves. If any of you wish to make a statement at the beginning this will be the time to do it.

Mr MacGiven: Nico MacGiven, Campaign Officer for National People First, an organisation for people with learning difficulties.

Mr Lee: I am Andrew Lee, I am a Director of People First. I have also been a trustee of POHWER, the advocacy agency in Hertfordshire which was awarded the ICAS bid for Hertfordshire. I have been in the self-advocacy movement since 1994.

Ms Aspis: My name is Simone Aspis, I am a Director of Changing Perspectives, we do dissipated quality training and consultancy on a wide range of issues around disability and support various campaigns on disabled people's rights.

Mr Downs: My name is Richard Downs, I work for Brent Advocacy Concerns as a coordinator. I am here today as a support to Changing Perspectives. I specialise obviously in advocacy.

Dr Collins: I am Jean Collins, I am the director of Values Into Action, which is a research and development organisation. I work purely to improve the prospects of people with learning difficulties.

Mr Brookes: My name is Mark Brookes, also of Values Into Action. I have been an advocate for self-advocacy groups all across the country around the White Paper and have been involved in advocacy for about 15 years now.

Q646 Chairman: Thank you very much. Did any of you wish to make a statement at the beginning, a short statement, or shall we go straight to questions? Shall we start with the questions? Can I ask you, you have seen the draft Bill and you have sent us some very, very helpful written evidence, could I ask you first what you do not like about the draft Bill?

Mr Lee: The general authority to act is open to abuse. Paid carers and relatives could say that we cannot make a choice because it is what is best for them rather than best for people with learning difficulties. This will go against the aims of more choice and control for people with learning difficulties in valuing people, for instance living independently or having relationships. It goes against the human rights, for instance rights to freedom, rights to family life and rights to privacy. Our members have told us about their relatives and paid carers bossing them about, this shows that it is unwise to put our faith in these people to really allow us to make our own choices. There is no easy way for people to complain. It is no good relying on social services' complaints procedures because they do not work and many people do not know how to use them. There is no complaints procedure for relatives or neighbours stopping you from making a choice.

Q647 Chairman: Thank you. Does anybody else want to comment?

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Ms Aspis: Continuing from the list we would like to build on the list that people have first set and we have identified some additional concerns. The first voice does not start from the perspective of a right to make decisions it starts with the perspective that people are unable to make decisions, so it does not start from the basis of rights. The definition of incapacity and also the difficulty in terms of defining what capacity is are both subjective, which means it can be open to abuse by relatives or anybody who could really reasonably decide whether somebody else has the ability to make a decision for other people. On the other hand if you go for an objective perspective you then start going back to IQ testing and other ways of assessing decision-making as to whether somebody has the capacity to make a decision. That cannot be the right way to do things because we all make decisions in different ways. It also starts from the place that people must always make a decision as well so therefore there seems to be no room for people who for one reason or another might choose not to make a decision. It also starts from the place where people might wish to say no to a choice that is being made. We also think there an assumption, it starts with a person's deficit, so a person is unable to make decisions, as opposed to looking at the reasons why somebody cannot make decisions based on external factors like communication support and past decision-making experiences. We also think it goes against the principles of the Human Rights Act.

Mr Brookes: A couple of things, one thing is it was not accessible for people with learning difficulties. The other thing is that it is supposed to be about valuing people, there is nothing in there about valuing people. There is no advocacy in there and there is nothing about planning for people.

Q648 Chairman: Would you think that since the Bill actually does say that everybody is assumed to have capacity and anybody who wishes to question it has to prove otherwise, do you not find that helpful that it is assumed that everybody has capacity and then you have to show people that they do not have that capacity? Do you think that is helpful?

Dr Collins: One of the problems with that is there is an assumption that you either have capacity to make a particular decision at a particular time or you do not have capacity to make that decision whereas in fact in real life all of us have varying levels of capacity round particular decisions. It is very seldom that we can instantly make a decision by ourselves, we tend to look for help, advice and support from other people and the amount of that support from other people will differ enormously between different decisions. One of the problems is that you assume that you have capacity or you lack it. There needs to be a provision within the Bill for people to be able to receive support, to use support to help them work towards making decisions in exactly the way that the rest of us do, although perhaps we need less support most of the time, but nevertheless many, many people with learning difficulties can reach a

decision if they are given, the kind of support that people need over a period of time and that takes into account their particular problems.

Q649 Mrs Browning: Could I just ask following on from that, how do you envisage that support helping people with a disability where they have difficulty conceptualising something that is outside their own experience because very often for that group of people if you give them a choice of two or three options they cannot visualise what that would mean to them as individuals. How would you see the support they need? Would you suggest that no decision should be made until they have been, say, taken to see what the three different housing options are or is that where the independent advocacy would come in?

Dr Collins: It depends on the type of decision they were making. If it is a decision about where somebody is going to live time does need to be taken to take people, perhaps not only just to see what the house might look like or the flat but to enable people to have the experience of living in it for a period of time in order to find out if it is something that they want to do. People need to have the opportunity to actually experience what is being offered to them. If it is a less important decision, if it is not such an important decision in someone's life they might not be able to vocalise their views but they will have a view, they know what their likes and dislikes are and people round them need to work with them to find out what it is that they like and what they do not like and how that can then be expressed in the decision that needs to be made. For example, how does somebody want to spend their days, should they go to a day centre or should they be supported to do a variety of different activities? The person may not be able to give a straightforward answer to that question but the people round that person knows when they go to the day centre they can become very distressed or when they go swimming they have a great time. It is about knowing the person and it is about using their reactions, which may be extremely helpful. What I am arguing about is that even in relation to one decision at one time somebody might initially appear not to have the capacity to make a decision but through working with that person, helping them experience different situations they can demonstrate what they like and what they do not like and what the person is indicating is itself a decision. You can bring somebody to the point where they can make a decision even though they are not verbally saying it.

Q650 Baroness Fookes: The Bill does actually allow for that, it seems to me it is concerned not so much with the wording of the Bill but as to how it might be implemented in practice?

Dr Collins: You say the Bill allows it, it does allow it but it does not say it has to happen and for people with learning difficulties it will not happen.

Ms Aspis: There are problems, it does not start from the right space. There are no rights, it does not say the right to advocacy, the right to decision-making,

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the right to personal centre planning, it does not specifically say those rights. It does start from a different place, it does not start from the right to make decisions and the support that is needed. In terms of the definition we would like to see something different from incapacity which may be kicking in with the process when somebody cannot make a decision as opposed to when a person is labelled to be capacitated because then it allows a much more objective view if they want to make a decision as opposed to whether the person is or is not able to do so.

Q651 Laura Moffatt: Mr Brookes you said something very interesting, you said the Bill itself was not accessible, I just wonder if anybody or you yourself could say how that could be better the next time or what lessons can we learn before the Bill comes before us? Coming out of the second part of that conversation I am clear in my mind that the Bill is more effective for those who lose capacity and for those for who decisions have to be made and already this debate in the short-term has exposed it is very different from having a learning disability. My sister has worked with people with learning disabilities, she now runs a bungalow for a health trust for lots of people who have learning disabilities and their decision-making processes are very different and I think we need to explore that much more today so that we can be very certain that this Bill is going to do the business for people with learning disabilities.

Mr Brookes: The first one first, I do not know if the group or whoever wrote this worked with people with learning disabilities, maybe you could work with people with learning disabilities to help write it so there is a lot more pictures, a lot more shorter words, not 120 pages long like the White Paper when it first came out, and I actually read that from cover to cover.

Q652 Laura Moffatt: You beat me.

Mr Brookes: Yes, it took a long time. I think that answers that question. Perhaps do not do just one draft, if a couple of things do not look right you can go back until they are. Your second question, I will give you a for instance, I was at the Orchard Hill Hospital—I went on behalf of another organisation, I belong to the National Development Team—and I was accompanying someone round. It is dreadful, it is a shocking place to go. Some of the people there could express when they were happy and when they were sad, we took one young man out and he was smiling all the time because there they do not get to go out much for walks. I think people can express it in some way. I have also worked with quite a few people on a one-to-one basis and if you spend time with them you have to be patient with them. You have to be patient with anyone who you work with, even Jean has to be patient with me! It is about understanding and a lot of the time knowing what they want. It can be done. Thank you.

Q653 Stephen Hesford: General authority open to abuse. Can you help us on this, does the Bill add to the current problems, ie what the common law currently does or does it add to it, is it the same as or is it better? At the moment I do not have a general understanding as to whether this Bill creates an offence by its very existence or whether it is just might be what you want in an ideal world?

Dr Collins: As is currently drafted in my view this Bill legalises what is currently done by and large unlawfully in terms of decision-making being done on behalf of other people. At the moment because the law is so unsatisfactory many, many decisions are made for people with no legal basis. This Bill if it were to go ahead would legalise that position without ensuring those decisions are what people want and without ensuring that people's views are properly and thoroughly taken into account, it would actually worsen the situation of people with learning difficulties.

Mr Downs: I would agree with that totally for people with learning disabilities. I think the Bill fails to recognise the reality of the lives of disabled people through general authority and it accepts that a lot of people have already shown they cannot be trusted with these best interests and are being put in a position where they can say, "I did this because I was acting in your best interests". If their best interests are the same as what I think is in my own best interests then I do not have any recourse through this Bill.

Q654 Lord Rix: Could I ask Mr Downs and Simone Aspis if there is so much wrong with the Bill they think we would be better off without it or would we be better off with a similar Bill but with a more positive approach to the problems you are listing. For instance instead of being called the Mental Incapacity Bill it was called the Supported Decision-Making Bill, and that was carried through the clauses of the Bill as a theme, would you consider that to be more acceptable?

Ms Aspis: Can I move on to ensure that Nico gets an opportunity to respond before I answer your question.

Mr Lee: This is in answer to Mr Hesford's question.

Mr MacGiven: The "General Authority" is too easy to abuse, it puts too much trust in relatives, staff and others to really support people to make their own choices. Lots of People First members have told us that relatives and staff do not support them to make their own choices. Our members told us that they are bossed about by relatives and staff and that decisions are made for them that are really best for the relative, paid carer or service provider. For instance, people who need support to go out will be stopped from going out by services providers because the service provider has not paid for enough staff to provide support for the person to go out. More authority will mean that over-protective relatives, paid carers and other people will be legally able to stop us doing things that we could do. Paid carers, relatives and other people will be able to use general authority to control people with learning difficulties to suit

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themselves. If challenged they just say that they thought the person with learning difficulties could not make their own choice and they getaway with it. Another problem will be that people will say that it was unreasonable for them to think that someone cannot make a choice just because someone has learning difficulties.

Q655 Chairman: Thank you very much, that is very helpful indeed.

Ms Aspis: I will answer your question, we would like to recommend a Supported Decision-Making Bill so it starts in the right place. It would be based on rights and the following rights would be: to make our own decisions, the support to make decisions, to communication support, to make mistakes, the right to advocacy, to make decisions without pursuing incapacity, to change our mind, to have a personal sense of money, to access supportive decision-making panels—

Mr Downs: I will talk about that later

Ms Aspis:—access to information, to explore decisions, which is what Jean Collins was talking about, the resources to make it happen, the right to say no, the right to complain and appeal and to know that bad practice can and will be penalised, to have decisions affirmed and the right to be respected for your self-interest.

Mr Downs: What is interesting about this is that Simone and I met yesterday with each other yesterday at 3 o'clock and by 8 o'clock we came up with this solution to this problem. I have a problem with the process because I do not believe enough disabled people and disabled people's organisations have been involved in the consultative forum. There is some difficulty because again the people who were typically assuming the general authority are the people who make the decisions for us, when we actually want to make them ourselves, and have been involved in the process. Having looked at the Bill from a position of rights we recognise the fact that we have to have a process that enables those rights to happen.

Ms Aspis: The way we would keep this in would be to first of all say that out of necessity a person can act on behalf of another, as they do at the moment within the common law and then the process will be kicked in as soon as there is any doubt about whether somebody can make a decision, as soon as somebody feels that a decision needs to be made on behalf of somebody else that is not necessary because this process will be kicked in.

Mr Downs: We are talking about a decision-making Bill which is for a supported decision-making power to be set up which when capacity is in doubt and it will act from a code of practice to be agreed as acceptable to disabled people. The panel shall have the power to provide guidance to the people involved. The panel would have the power to review any decision which is made in the name of best interest and it would have the power to call for an independent complaints panel and an appeal. It would have an obligation to create a stir if it registered something like a court of protection, and

I acknowledge a court of protection has often failed disabled people. It would have the power to initiate a decision-making assessment of the recommendations from which it must be implemented. Again we say that advisedly inasmuch as local authorities are not recording the feelings of disabled people. It would have a responsibility to ensure that our rights based framework is observed. The person who would make a best interest decision would also be able to seek a second ruling from the court if people's opinions are in conflict. The reason we are proposing to have a Bill like this and a process like this is because basically common law has failed to protect the interests of disabled people.

Q656 Lord Rix: How would you protect the people with a learning disability, who had profound and multiple disability, because going through a bureaucratic process would be virtually impossible at any sort of speed? How do you deal with that?

Ms Aspis: We basically see this as a similar model where a court rules when a young offender gets convicted there is the first time offenders panel and they will meet regularly with that person to help them and this would be the same order for disabled people who need support making decisions. The benefit would be that in an on-going process where they would be reviewed, people would be involved or a programme would be set up, so it would not be like the court deciding this person is incapable somebody else has to make that decision, it is usually one person makes that decision under general authority. This will give more safeguards towards people who have profound learning disability because there would be more people acting in their interest than one person.

Mr Lee: In relation to your question, the Bill could give a right to communication aids that people need with enough funding to do this properly. Paid carers and relatives should have proper training and support from communication experts so they are able to deal with the communication needs of people who find it hard to speak up. People who have communication difficulties and whose ability to make their own choices is being questioned should have an independent citizen advocate.

Chairman: You are answering quite a number of the questions we were going to ask you, we are doing very well on the framework of questions.

Q657 Mrs Browning: I want to put to you scenario, if I may, I listened very carefully to what most of you have said. In terms of the parent I am must declare an interest, I am a parent and whether I am dealing with issues to do with my son who does have a learning disability or my other son does not we very often disagree quite vigorously on all sorts of matters, and I think that is life and that is always going to continue. I fully understand why you are making the case for your own independence free of what in your verbal and your written evidence you describe as "parents have a view". In one piece of evidence you say they might take a decision because of the financial implications for the person, I fully

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understand that. There is a worry for parents, and it is this, parents also feel they have a responsibility and it is a lifelong responsibility and sometimes third parties make decisions also based not on their knowledge of that individual but on the resources that are available to someone. It has been put to us in this Committee some of things you are advocating and some of the things that other witnesses have advocated to be incorporated into the Bill, I am not saying that is a the bad thing, I think that is a good thing but there would need to be a huge amount of resource behind this Bill for it to work because if they were there we would go back to the old business, a situation I find very unsatisfactory, that, for example, social workers are employed by the very people who provide the service and I do not believe they can represent you as the advocate. What do you do, and this is my question, Chairman, about the parents who are themselves very elderly still caring at home for the adult with the learning disability where that adult with the learning disability flatly refuses to become involved in any form of independent living because those parents as they get older know they are going to become frail, die within a matter of a few years and yet unless things are put in place during their lifetime for the person, the adult with the learning disability, it then becomes a decision taken in a crisis. This happens all too often and any decision taken in a crisis does not usually offer choice and does not usually offer appropriate provision. Where do we get the balance between parents who are trying to provide during their lifetime for adults and the needs you expressed very articulately today for your own independence, where do we strike the balance in the Bill?

Mr MacGiven: I am not complaining but if the person with the learning difficulty is living with an elderly person and if that person wants to live independently the elderly person would say, "you cannot do that because I will not get my pension otherwise".

Q658 Mrs Browning: I will agree they do sometimes but equally there are adult-dependent children still living at home with very elderly parents who out of fear or even a lack of resources themselves would be very afraid of making that big step, and it a big step, from the security of the parental home to independent living. I think that is quite a worry and problem for parents who can see that if it is not done in their lifetime it will be done under circumstances that will not necessary be in that child's interest.

Ms Aspis: Which is the reason why we would like to see a Supported Decision-Making Bill, where that decision-making starts from a much younger age than 16 and therefore you start that process of helping people to make decisions. This whole idea about resources seems to me to be about the priority of how we spend our money. If we are really committed to the fundamental rights of all humans beings to live with dignity then we must resource it. We do have the money out there in other governments departments that could be more usefully spent in doing things in terms of people

making those decisions and to experience different ways of living and then it does not get to crisis point when a decision has to be made and where the person with learning difficulties is unable to make the choice.

Mr Lee: The thing is when people with learning difficulties are actually born the first thing many parents are actually told is your son or your daughter will never walk, never talk, they will be a complete cabbage for the rest of their life and the best thing to do is stick them in an institution, which is what my parents were told. The thing is that doctors and nurses and the medical profession generally start from the point of actually telling parents that their son or daughter will not be able to do things, which is completely wrong. The medical profession are using their strength to actually dash the hopes of parents at the very beginning and their aspirations are dashed and that is because doctors and the medical profession generally are not educated in the social model. I think that is something that Parliament could do as far as educating our medical profession so that they start from the position that a person with learning difficulties will be able to achieve things rather than the position of they will not be able to. If parents are actually given the confidence and are told that they will be able to do things and the information is accessible and it is there right at the very beginning, where they sit down with someone and they say "this is available, this is available and this is available and this is how you go about doing it" then their confidence will be boosted and their attitudes towards disability will be positive rather than negative and the person with learning difficulties for the rest of their life are fighting their parents and society generally. There needs to be a massive education programme and you need to put people with learning difficulties at the heart of it. All forms of advocacy needs to be at the heart of government policy if we are going to change decades of the way which society perceives disability, which is completely wrong. We are fighting against so many things and there is so much this Parliament can actually do about it.

Q659 Chairman: Okay. Would you agree that applies with all forms of disability.

Mr Lee: I agree with that but people with learning difficulties also have difficulties within the disability movement. If you take Mr and Mrs General Public when you talk about disability they think deaf, visual impairment, a wheelchair, not learning disability because learning disability is invisible unless you have Down's syndrome and that is actually wrong. If you have a strong point of view and you happen to have a learning difficulty then there is a kind of bracket that society tries to put you in and try to reduce you, your view is actually worth less than a person who does not have a disability.

Q660 Chairman: I think Mr Brookes wanted to say something.

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Mr Brookes: Regarding your question round the scenario, about what that person wants, if he is happy then maybe he could stay where he is or if not something can be done so that he can get the right attitude of moving out independently if time is spent with him so that he has options.

Mrs Browning: Okay, thank you.

Q661 Huw Irranca-Davies: A very straightforward question, I listened with interest to what you were saying so far, in terms of the individual rights of people within your organisations is this Bill a retrograde step? Is it simply a formalisation of what we currently have in the common law or is it an improvement in terms of the individual rights?

Mr Lee: In the words of our members at our AGM, which we held in August, this Bill will set the self-advocacy movement and the advocacy movement back 20 years. That is the view of our members.

Q662 Mr Bercow: Mr Lee you have just made reference a few moments ago to self-advocacy, reference has already been made to advocacy and you referred to it again in very stinging terms just now, I wonder if building on what you just said I can ask you in as precise terms as one can what given a freehand you would like the draft Bill to say about a person's right to help from an advocate and if you can exemplify what in a practical situation the difference would be? With what frequency should there be such access, on what terms, et cetera, at different stages of decision-making? If you can try from my point of view as a layman to exemplify what the practical difference are. I am very, very struck by you saying this sets us back 20 years, what would set us forward 20 years?

Mr Lee: There should be a mandatory right to an independent advocate whenever a person's ability to make a decision is questioned.

Chairman: That is very succinct.

Q663 Mrs Browning: Can I ask you, this Bill has been seen to be a Bill that would resolve a problem which is not infrequent and was typified by the *Bournemouth* case, where a young man with autism was taken into the mental health inpatient services and sectioned under the Mental Health Act and where the only people really who knew him well enough were the advocates on his behalf, his carers with whom he lived, were denied access to him and were not listened to by the medical profession who made decisions about him. It is a case before the European Court now. We are told that this Bill will resolve that sort of problem and I just want to ask you if in those set of circumstances an independent advocate be as effective as the people with whom that young man had lived for many years?

Mr Lee: I think they would be more effective, an independent advocate would be more effective because an independent advocate would be able to take a step backwards because sometimes if you are too close to a situation you cannot see the whole picture. If I might be able to give you an example. I actually helped a friend of mine who has a learning

difficulty and has a mental health problem as well. What we found was that the people who support people with mental health problems are not trained and do not understand people with learning difficulties and those who support people with learning difficulties are not trained in mental health. The result is you get a yo-yo situation between mental health people who say, "it is not my responsibility, it is the learning difficulties people who are supposed to support people with learning difficulties" and they say, "it is not my responsibility because you have a mental health problem". The result is that a lot of people with learning difficulties who have mental health problems do not understand how the Mental Health Act actually works and so people that are supposed to actually be there to act in their best interest end up making decisions for them because it is quicker. It is quicker to make a decision like that rather than involve the person and take the time to actually make sure that they do to the best of their ability at the time. There is not such a word as "cannot", a lot of people say "we won't" and that is people's problem if they think that you won't or that they can not be bothered to actually sit down with a person with learning difficulties and go through their options because they are time pressured, they have too much on their hands. Based on me helping my friend I can tell you that the Mental Health Act fundamentally lets people down with learning difficulties and who have mental health problems.

Q664 Mr Bercow: I just want to pursue this, this really is the nub of the matter, your explanation that an advocate should be available whenever a person's capacity to make his or own decision is questioned was admirably succinct and clear but it is clear as a point of procedure rather than as a point of effectiveness, what I mean by that is presumably your insistence on this entitlement, which is very clear, will be effective only if the balance of power provided elsewhere in the Bill is changed. In other words, you can have an advocate—who tend to be paid by the word—and on any occasion you care to name, you may think it is a matter of proper procedure and someone is entitled to such an advocate and they should be available but unless the principles of the Bill and power relationships of the Bill, in terms of who is authorised to determine best interests, change in accordance with what you probably prefer it will not make as much a difference as you want. I am sorry if I have not expressed that clearly.

Mr Lee: Okay. The thing is that our view is that parents or carers cannot be independent advocates because they are too close to actually make sure that the person with learning difficulties has a number of choices, a number of choices to the best of their ability. We now have enough technology today to make it possible to actually give people with learning disabilities with high support needs the ability to make sure their own decision rather than a case like, if I can give an example of one of our members that spent most of his time, apart from going to a day

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centre, sitting in front of his four walls because the local authority that he lives in says that it is too expensive to give him choices because the level of support he needs requires two support workers. The result on paper says that he should have choices but in reality he has no choices at all and he actually put an article in our newsletter to that effect because he can make his own decisions but because people actually cannot be bothered to sit down and understand his communication difficulties, where people who are experts in communication can train the people that support him closely and can actually help him to make those decisions which would result in him living a fuller life and doing what he wants rather than what the local authority can afford.

Dr Collins: I wanted to come back in the *Bournewood* case, the question was would this Bill solve that particular problem? In my view it would not because the man who was taken in would still have been taken in under the authority of the psychiatrist in the same way that happened this time. It would be worse for L because this Bill would have given the hospital the authority to do it whereas in fact it was questionable that they did it because he was taken in as a voluntary patient when in fact according to the people who knew him best he was not voluntary because of all of time he was in there he lost weight and became very distressed, and so on. So I do not think this Bill will have solved that problem. What would go a enormous way towards solving all kinds of problems for people with learning difficulties and for their families is to involve in the life of the person with learning difficulties other people besides purely the family or purely social services or those officials, formal people who are involved. If decision-making in somebody's life was something that was done with the person with learning difficulties, with the family, with any services or others and with an independent advocate who can have an overall view of the situation you not only have the situation where there is automatic monitoring and safeguarding of the person but you have other people involved in those circumstances who can question each other, "Why do you recommend this? Why do you think this person wants that?" That can be going on all of the time. You can also share the responsibility so when you reach a stage where the parents are getting very old and reaching a point where they can no longer care or reaching a point where they really want to see their son or daughter settled somewhere else you have already got other people involved in that person's life and decision-making is shared round, it acts as a safeguard. You can also use this structure to help supported decision-making, which is an essential feature for people so that they can be brought to understand the decisions that are being made.

Mr Downs: The atmosphere in the room for the last half hour has been electric because you have disabled people and representatives of disabled here. In terms of best interest the people that you have invested your trust in in the past in common law are suspect and it does not necessarily work in our

interests. On what Angela was saying, if carers came in and were involved and had a better idea. There is a tension there and that tension can go back to, "is this person capable of making a decision? If they are not capable am I responsible, am I doing the right thing, am I protecting this person?" That is exactly the reason we are talking about the process, whereby the responsibility for that person's rights are set. It would be recognised in Lord Rix's point that there is an issue about time and there is an issue about bureaucracy and the difficulty that would cause. We are saying our lives are worth protecting, our lives are valuable, the situation as it stands now is potentially very, very damaging to us and it is time for a change. The Mental Incapacity Bill as it stands at the moment is retrograde because it only confirms the current situation, it does not confirm the rights that we should have.

Q665 Lord Pearson of Rannoch: I wonder if I can put a question to Dr Collins, then a secondary one to the rest of the panel. I hope the question does not seem pedantic. In your researches and your research activities have you sort of attempted to cost your proposals, particularly the advocacy side of the proposals? We can all agree that the money ought to be there for whatever the right solution is but one has to wonder whether it will be. Secondly, speaking as a parent of a daughter with severe intellectual impairment, my daughter could not possibly sit on this panel today and partake in this really excellent performance. Can I ask if you can appreciate our worry as parents that your proposed advocates may not in fact in the end come to act in the best interest of our family member who, forgive me, as I think many of us feel, we do know better than all of the professionals put together. I admit, of course, you are right; there will be some parents who get it wrong, perhaps with the best intention in the world, perhaps not, but I think many of us feel that on the whole as parents who have been caring for their children for many, many years—I am targeting the question on the severely intellectually impaired or those with severe learning disabilities or mental handicap, whatever you want to call it—can you understand that from our point of view? Dr Collins, first, what about the money?

Dr Collins: Your first question, we have not costed it. What we are talking about is what systems could be put in place, what can be put round people, people themselves, ie are the people with learning difficulties going to feel comfortable, who are the people in their natural networks who should be involved in the decision making. What we arguing are that it is not right for one person to be in control of another person's life and that decision making needs to be shared and incorporate the views of the person with learning difficulties however severe the learning difficulty maybe. I think it is irrelevant how severe the learning difficulty may be as far as their view is incorporated into the decision making is concerned. However severe the learning difficulty may be everybody has a preference, everyone has a like, a dislike which can be discovered, which can be

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found out by people working that person. It is essential that that person's views are elicited, discovered and do hold a central point in all of the decision making.

Q666 Mrs Browning: I want to test again this question of carers and parents, again coming back to the Bournemouth judgment, do you realistically think that independent advocates would continue to challenge the views of the psychiatrists to the extent that they took the case to the House of Lords and on to the European Court or do you think that, for example, as in many parents do just trying to get the right package of support, the basics where they challenge social services and health and ultimately very often this is happening all too frequently in my casework and if they do not get their rights they test it in the court. I raised this with Social Services when they gave evidence to us because increasingly Social Service departments are finding themselves challenged in the courts, and I think quite rightly so, are independent advocates and independent witnesses going to have the resources to take a case that far or are they going to succumb to what the doctor says in his professional opinion is the case of L of X or whoever?

Dr Collins: The position is that there needs to be a range of people involved in the decision making for somebody it is not a case of this person or that person, it is a case of a range of people involved which would be the family, the foster parents in their case, foster family, and it would be the independent advocate because you need that range of people who can see things from different perspectives actually saying what they think the person actually wants. What we have to remember is that the important person is the person in the centre, the person with the learning difficulty and how do we get what that person wants. In the Bournemouth case, nobody, apart from the people he lived with, nobody was asking what is best for this person. We have been talking about best interest decision making I know that is what in the Bill. What about decisions being made that benefit the person, which is what the Adult with Incapacity Act in Scotland says, "no decisions are made unless they are of benefit to the person". That is different from best interest. It puts the person clearly at the centre. You cannot intervene in somebody's life unless you can clearly demonstrate that it benefits that person.

Mr Lee: The main difficulty with this Bill is there is no formal complaints procedure. There is no way of challenging a decision that has been made that you disagree with. In Scotland, the systems that they have been swamped. When I asked Rosie Winterton, MP, about how you would deal with this, she said, "We do not really know." If you had a decision made for you and you disagreed with it, you would want to complain, would you not? This Bill is saying there is not any complaints procedure. Plenty of our members have tried to use the existing complaints procedures that are around at the moment but they have not been taken seriously. The complaints have not been properly followed through they way that

they should be. The existing system does not work for people with learning difficulties. There needs to be a way in which people with learning difficulties can challenge things. I used to be a lay assessor for Hertfordshire Inspection Unit and I found that people with learning difficulties living in a wide range of residential homes raised issues with me that they would not raise with an independent person who did not have a learning difficulty. It opened a can of worms for the local area that I was in. The only reason this came to light was that people with learning difficulties were able to speak to independent people with learning difficulties that they felt they could trust and something would be done.

Q667 Baroness McIntosh of Hudnall: You talked about people with learning difficulties because that is what you are here to represent. The Bill does not only seek to serve the interests of people with learning difficulties. It seeks to serve the interests of a number of other people who, for different reasons, suffer either permanently or temporarily from difficulties in making decisions. Would you say the same things that you said on people with learning difficulties about all those other groups as well?

Mr Downs: I work for a disabled persons' organisation and everything I have said in this room has been said about disabled people.

Q668 Baroness McIntosh of Hudnall: You would include people who suffer from injury and are incapacitated as a result of that or people who suffer from dementia, having been people with capacity who have become people without capacity? Everything that you have said on behalf of people with learning difficulties you would equally apply to those other groups, would you?

Ms Aspis: When we did our support on the decision making in the Bill, we had all disabled people in and this structure we propose would ensure that the responsibility for decision making is shared and that it would be based on self-interest as opposed to best interest of that person. We understand our self-interest is likely to be different from other people's perception of what is best interest. We also think that this panel will be flexible enough to take on the needs of people who may be temporarily incapacitated. If they have depression, they will be involved in the decision making process for a limited time and then, once they are well enough, the panel would not be needed any more. You can see how it could be used for people who might be temporarily incapacitated in the traditional sense. We would like to stick to people who temporarily cannot make decisions or people who are unable to make particular decisions at that time as opposed to being incapacitated.

Q669 Baroness Knight of Collingtree: The Bill has to deal with a great deal of variation and this is one of the problems. I was immensely impressed, reading about Mr Mac Given who said he had been bossed about by people telling him what to do, what to eat,

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what to wear and where to go on a day to day basis. That struck horror into my world when I read that. Realising the variety of cases that we are trying to deal with here in the Bill I come on to what was said earlier on about the concerns on the general authority. I particularly put the question to Dr Collins because these words too which you put to us are extremely chilling: "The general authority represents a potential threat to the safety, satisfaction and well-being of anyone at risk of being judged to lack capacity." When you went on to tell us about what ought to be done, which is not being done, you mentioned that there should be a range of individuals. Is it that you feel that the fact that there is no overall plan for the person agreed by everyone; that there is no form of monitoring how the person is getting on under all these rules and, finally, I think Mr Lee said earlier there was no way to complain?

Dr Collins: Absolutely. The reason I say that it puts people at risk is that under the general authority it would be perfectly possible to have just one person making all the decisions for another person without anybody else having any input, without anybody checking to make sure that the person was happy with those arrangements, without any outside influence at all. There is no monitoring. There is no way of checking if the decisions being made are what the person wants. There is no way a person can complain or challenge. How do you, as the person who is said not to have capacity, challenge the person who says that you do have capacity? Under the general authority the person who takes on the general authority does not even have to submit to the assessment about someone lacking capacity. People are assumed to have capacity until proved otherwise unless you come under the general authority because then all it requires is for somebody to reasonably believe that you lack capacity, with no formal assessment. As long as somebody reasonably believes that you lack capacity, they can make any decision whatsoever provided that they reasonably believe that it is the right one.

Mr MacGiven: There should not be a general authority because when I went to complain there were still no better complaints procedures. When I tried to make a complaint about things to do with my life about people bossing me around, the point was not taken up.

Q670 Mrs Humble: As somebody who has worked over many years in developing advocacy services and as the president of Blackpool Advocacy, I have become a little concerned that in this debate about advocacy not everybody understands what the Independent Advocacy Service does. Do you agree that it is important that, if we do say to government, "This Bill should have references to an independent advocacy service" we define what we mean by it and that the advocate is the voice of the individual? It is not somebody who says what they think is in the best interests of the individual; it is not somebody who

looks at the situation in the round and is weighing up professional, clinical judgments and the individual. It is the voice of that person. Do we need an advocacy service? If so, how should it be defined in the Bill? Secondly, would some of the concerns that you have outlined be satisfied if there is a comprehensive statement of principle at the beginning of this Bill that also links in to, for example, the *Valuing People* document that the government published two or three years ago? That makes very clear references to people with learning disabilities and the need for advocacy services to represent them. This Bill has been presented to us as a very narrow legalistic document. It clearly covers people in a non-legal setting, in a non-clinical setting, in a community setting. How can we make it work for you and the people you represent?

Mr Brookes: There has been a big debate on the definition of advocacy and it is still going on. I do not think you can get a clear definition. Several organisations have their own definition of what advocacy is. That debate will go on for years. Regarding *Valuing People*, I think it should be put into this Bill. It is not in it. It all depends on people's circumstances, where they are living and how they can make decisions if they are capable. We did some research around decision making which will be sent to you. I did a workshop. I did a tour all over the country and spoke to about 200 people with learning disabilities. There was a wide range of people who were living at home, in a hostel, or in a shared home. They were happy with some of the decisions that were made but they were not being listened to.

Q671 Chairman: You say that it may take years; we have until the middle of November.

Mr Brookes: I heard it had been extended for another two years.

Mr Downs: Bearing in mind the importance of the timing, I have been involved in advocacy for 12 years. Defining advocacy has been difficult for the advocacy movement. I remember I attended a meeting which came with a two page definition of what advocacy was which I found quite helpful, obviously, but Advocacy Across London has devised an advocacy charter which something like 130 advocacy groups have signed up to. In that charter it says that advocacy is taking action to help people say what they want, to secure their rights, represent their interests and obtain services that they need. Advocates and advocacy schemes work in partnership with the people they support and they take their side. Advocacy promotes social inclusion, equality and social justice. That is a pretty fair definition.

Chairman: That is an excellent way in which to finish what has been a very helpful session. I speak for all my colleagues when I say that this has been very thought provoking for us and it will be extremely helpful when we come to draft our report. Thank you very much indeed.

35. Supplementary memorandum from People First (MIB 1224)

GENERAL QUESTIONS

1. *What don't you like about the bill?*

The General Authority to act is open to abuse.

Paid carers and relatives could say that we can't make a choice, because it is what is best for them rather than best for the person with learning difficulties. This will go against the aims of more choice and control for people with learning difficulties in Valuing People, for instance living independently or having relationships.

It goes against our human rights, for instance right to freedom, right to family life, right to privacy.

Our members have told us about their relatives and paid carers bossing them about, this shows that it is unwise to put faith in these people to really allow us to make our own choices.

There is no easy way for people to complain. It is no good relying on social services complaints procedures, because they do not work and many people do not know how to use them. Also if it is a relative or neighbour stopping you from making a choice, there is no complaints procedure.

2. *What do you think is good about the draft bill?*

It is good that it says we should be supported to make our own decisions. But on a day-to-day basis in the places where people with learning difficulties live and spend their time, how do you make sure that relatives and paid carers keep to that?

HELPING PEOPLE TO MAKE CHOICES

3. *Can you think of any ways the Draft Bill could make sure that people are really supported to make choices for themselves?*

The bill should give a right to independent advocacy whenever some-one's ability to make their own decisions is questioned.

People with learning difficulties going into places where other people with learning difficulties live or spend their time to ask them if they are allowed to make their own choices. Service users with learning difficulties are more likely to feel comfortable about speaking up to another person with learning difficulties.

Training and information for people with learning difficulties by people with learning difficulties, about their rights to make their own decisions and what to do if people stop them making their own decisions.

A right to non-means tested legal aid to help people to go to court if they are being stopped from making a choice.

4. *How do you think more about Person Centred Planning should be included in the bill?*

The bill should say that people who are supporting people to make their own choices should use Person Centred Planning to find out what people with learning difficulties want when they need to make a choice.

5. *Can you think of any ways the Draft Bill could make sure that people with communication difficulties are supported to tell people what their choices are?*

The bill could give a right to the communication aids that people need, with enough funding to do this properly.

Paid Carers and relatives should have proper training and support from communication experts so they are able to deal with the communication needs of people who find it hard to speak up.

People who have communication difficulties, whose ability to make their own choices is being questioned, should have an independent citizen advocate.

6. *What would you like the draft bill to say about people's right to help from an advocate?*

As we said earlier, the bill should give a right to independent advocacy whenever some-one's ability to make their own decisions is questioned.

THE NEW "GENERAL AUTHORITY"

7. *If the Draft Bill became law, can you tell us about any problems you think might happen because of the general authority?*

The "General Authority" is too easy to abuse it puts too much trust in relatives, staff and others to really support people to make their own choices. Lots of People First members have told us that relatives and staff do not support them to make their own choices. Our members tell us that they are bossed about by relatives and staff and that decisions are made for them that are really best for the relative, paid carer or service provider. For instance, people who need support to go out will be stopped from going out by service providers because the service provider has not paid for enough staff to provide support for the person to go out.

The "General Authority" will mean that over-protective relatives, paid carers and other people will be legally able to stop us doing things that we could do.

Paid carers, relatives and other people will be able to use the general authority to control people with learning difficulties to suit themselves. If challenged, they can just say that they thought the person with learning difficulties could not make their own choice and get away with it.

Another problem will be that people will say that it was reasonable for them to think that someone cannot make a choice just because someone has learning difficulties.

8. *Do you think the 'General Authority' should stay in the Draft Bill?*

NO!

9. *If you don't think so, is there a different way to make relatives and carers understand what they can and cannot do when making choices for other people?*

The bill could say that people must support people to make their own choices using guidance like Person Centred Planning and the supported decision making guidelines done by Values Into Action.

The bill could say that relatives, paid carers and other people have a duty to involve an independent citizen advocate if a person with learning difficulties is finding it hard to make a choice.

10. *If the 'General Authority' stays in the Draft Bill how might it be made better?*

We think the general authority is unworkable and dangerous no matter how many safeguards you put in, because some people will always do their best to get around the safeguards.

11. *Do you think the Draft Bill will make sure that the choices made for people with learning difficulties are really in their best interests?*

There should be a monitoring system to make sure that decisions being made by a court appointed manager are really in someone's best interests and that they are only making decisions for the person that they are allowed to make by the court.

The government would need to check the monitoring system is working properly.

If a Court Appointed Manager makes decisions that they shouldn't, they should be replaced.

The likelihood of conflicts of interest should be highlighted. (Bone Marrow donation example)

Having access to an independent citizen advocate and non-means tested legal aid is essential.

If there is a dispute between the independent citizen advocate and the court appointed manager there needs to be an arbitration service as well as the option of going to the Court of Protection for a decision.

COMPLAINING ABOUT CHOICES THAT SOMEONE MAKES FOR A PERSON

12. *Can you tell us about any times when your members have successfully complained about choices that someone else has made for them? How did they do this?*

We know of lots of examples where People First members have tried to complain but have not been successful, the complaints systems don't work well for people with learning difficulties. (Nico's example)

13. *Can you think of any ways the Draft Bill could make it easier for people to complain if they are being stopped from making choices, which they think they should be allowed to make?*

Mandatory right to an independent citizen advocate with proper funding so there are enough advocacy services.

Access to non-means tested legal aid. (Training for solicitors by people with learning difficulties.)

Information campaign for people with learning difficulties about how to complain including training sessions by people with learning difficulties.

14. *Do you think that people with learning difficulties should help to train the judges and staff who will work at the new Court of Protection? What sort of training will they need?*

Yes!

Training would need to cover:

- Judges having links self-advocacy groups
- Working in an accessible way.
- Realities of life for people with learning difficulties about being controlled and bossed about.
- The power imbalance between people with learning difficulties and their relatives, paid carers and other people.
- The conflicts of interest that often occur between people with learning difficulties and paid carers, relatives.
- How important it is to listen to the evidence of independent people like citizen advocates, stress that advocates cannot be relatives or paid carers.
- Some people with learning difficulties have learnt to be helpless and dependent because they have not been allowed to do things for themselves.
- Using intermediaries.

36. Supplementary memorandum from Values Into Action (MIB 1218)

Mark Brookes and I would like to thank you and the members of the Joint Committee for your interest and attention at the oral evidence session on 21 October. We also wish to provide the following clarification of some of the points we made.

1. The general authority would make lawful what currently happens unlawfully. It would also remove the few safeguards that now exist for people whose carers (whether family members or professionals) regard them as lacking capacity.

2. Decision making is a process, not an event. Supported decision making takes people through that process, whatever their degree of disability, by enabling them to identify and indicate their preferences, views and choices. Substitute decision making, by contrast, merely substitutes the views of another person.

3. Our research has shown that collective decision making provides monitoring and safeguarding, as well as sharing the burden of responsibility. Decisions for others should be taken together by at least two people and preferably three, for example, by a family member, a paid carer and one other, perhaps a friend or a health or social services professional.

4. A right to advocacy should be on the face of the Bill. This would not require that every person deemed to lack capacity should have an independent advocate allocated to them, but would merely give them a right of access to an advocate. It would not have the severe financial implications feared by the Joint Committee.

I hope these points are helpful. I would be happy to provide any further information or clarification that may be required.

Dr Jean Collins

October 2003

37. Memorandum from RESCARE (MIB 61)

SUMMARY

Run by families for families of people with a permanent mental handicap/learning disability we represent through our affiliated groups, individual and family membership, thousands of such caring families and their dependent sons, daughters and relatives.

Through meetings, surveys, newsletters and direct contact we are able to assess and present their views, areas of concern and aspirations born from what is for them a life long commitment of love and experience with some 70 per cent doing the caring in the family home and increasingly so.

1. In the context of the above we welcome the long awaited Mental Incapacity Bill as applicable to people with a permanent mental handicap/learning disability who by any rule lack capacity, many of whom suffer a greatly reduced mental age, and for whose families the making of decisions is also a life long process of challenge.

2. We fully endorse and welcome the ongoing recognition of the necessity for the appointment by a Court of Substitute Decision Makers to be now renamed "Deputies".

3. We note and suggest to be carried forward the recommendation of the Law Commission in the Green Paper, "Who Decides 1997" ie "The Law Commission envisaged that the Court would be more likely to appoint as Manager (now Deputy) a family member or other carer", (page 57).

4. As within the Law Commission's Draft Bill 1995, Green Paper "Who Decides 1997", and Consultation Report 1999, Deputies should have access to healthcare records and other personal information; these being essential in carrying out his/her responsibilities in respect of the best interests of the person on whose behalf they are charged to act.

5. Legislative terminology should we feel leave no doubt as to factual representation. The general use of the term "carer" is open to confusion in its application and the terms "Family Carer" and "Care Worker" would give a correct differentiation between the two.

6. The Mental Incapacity Bill when given Parliamentary assent will obviously stand for many years. As Parliamentary Secretary Lord Filkin CBE says in his Foreword "We need to be confident that it would in reality deliver all the practical benefits that we intend". For our dependent sons, daughters and relatives it is the first time that legislation has taken in their real needs and even more so their protection. With the above points to be considered, we give it our blessing.

SUPPORTIVE OBSERVATIONS

7. We welcome the proposed Mental Incapacity Bill. People with a mental handicap/learning disability need life long care and support to a varying degree according to the extent of their disabilities. The Bill will clarify the Law and fill the vacuum that has long faced family carers whose dependent relative suffers incapacity.

8. A major factor consistently recognised within case law, but omitted in the proposed legislation is the often greatly reduced mental age of the majority of people with a mental handicap/learning disability and its ramifications added to the issue of incapacity and hence the case for Extended Minority and their on going protection beyond the age of 18 years. It is important to recognise that adulthood is not the arrival of an age of majority (18) but is the attainment of intellectual, psychological, social and sexual maturity. It also means being aware of one's rights and the social responsibilities which goes with these rights. It does not follow from this that a lesser value should be placed on adults with a mental handicap/learning disability but a recognition that their life long needs are indeed special and different.

9. The normal age of majority is obviously inappropriate for a severely mentally handicapped person whose mental capacity in all, or most regards, is that of a young child. It cannot be considered disrespectful to give such individuals the protection already afforded a child. This does not mean abrogating any views or opinions of the person with a mental handicap may have. Indeed parents continually consider the views and opinions of their normal children before they attain majority.

10. There is a danger of the dilution of the caring family influence, as suggested in some circles, fashions come and fashions go, caring families do not. The DOH local authority Circular "Social Care for Adults with Learning Disabilities" in "Links with Family" said "the most important life long stable relationship for many people with a learning disability is the relationship with their families and it is important that this should be maintained". The Westminster White Paper "Valuing People" and its statutory guidance gives encouragement and hope of immediacy to the families and rightly acknowledged that "caring for a family member with a learning disability is a life long commitment which continues even when the person is living away from the family home. Carers (family carers) make a vital contribution to the lives of people with learning disabilities, often providing most of the support they need". "Valuing People" goes on to say "statutory agencies do not always properly recognise the extent of carers (family carers) contribution or its value. Carers (Family Carers) face many problems and challenges. They need to be treated as valued partners by local agencies not as barriers to their son 's or daughter's independence."

11. This Incapacity Bill (2003) will obviously stand for many years and so the strength of the family role must be uppermost.

12. At the recent Care Standards Tribunal "Alternative Futures Limited v National Care Standards Commission June 2003. Judge David Pearl emphasised the importance of meaningful family involvement, real choice and the application of Common Sense as his Tribunal rejected the Alternatives Futures Limited appeal against the deregistration of care homes.

13. There has been a consistent failure to recognise the values that tie such families to their dependent member—values that need to be acknowledged as a meaningful part of the care equation and which can be best met in a monitoring and substitute decision making role. The ultimate goal is surely and simply one of care, satisfaction, contentment, and general well being leading to the happiness of society's most vulnerable and dependent members and that of their families whose role is firmly interwoven.

14. Our families and dependent relatives desperately need and fully deserve the long awaited support of the effective, clear, simple and informed Parliamentary legislation envisaged by the Minister.

15. The Bill has the one off opportunity to so deliver and in welcoming also the establishment of the Parliamentary Scrutiny Committee we ask its members to give its fullest consideration to the uniqueness of our area of concern and the expertise of the caring family unit in the decision making process.

16. For they, and their dependent relative their life's improvement is the longed for prize bringing light to the end of a long tunnel of endeavour to make it so. Give them your confidence and your support.

17. We are grateful for the opportunity to place before the Committee our submission and wish its members well in their deliberations.

August 2003

38. Memorandum from Care UK (MIB 1202)

1. INTRODUCTION

1.1 Care UK plc is pleased to make a written submission to the Joint Committee on the Draft Mental Incapacity Bill.

1.2 Whilst broadly welcoming the draft Bill, our submission is not intended to focus on the detail of its wording, rather it is intended to identify practical operational issues, which we consider, will be relevant when considering its implementation.

2. CARE UK PLC

2.1 Care UK plc is a leading independent provider of health and social care services. We operate as a specialist care outsourcing business working in partnership with the NHS and Social Services to deliver health and social care solutions across the UK.

2.2 Care UK plc has two operating divisions, residential care and community care, both of which provide care to a range of people including older adults with physical and mental health needs, adults with learning disabilities and adults with severe and enduring mental health needs.

2.3 Today Care UK provides care to more than 3,000 people in 75 residential and nursing homes, provides over 40,000 hours of homecare support a week via 35 home care branches and employs over 7,000 care staff across the country.

2.4 Care UK plc has also, as part of a joint venture with Afrox Healthcare Limited, recently been appointed preferred bidder for the provision of three Diagnostic and Treatment Centres.

3. PERSONS WHO LACK CAPACITY

3.1 Care UK plc supports the principle set out in the draft Bill that a person must be assumed to have capacity unless it is established that he/she lacks capacity. This is consistent with the delivery of high quality person centred care and should ensure the involvement and empowerment of the service user in care planning.

3.2 What is not clear from the draft Bill is how capacity will be assessed and by whom. This could cause confusion and potential conflict between care providers and carers if not addressed either within the Bill or within the supporting code of conduct.

3.3 Care UK plc welcomes the inclusion of clause 4 relating to decisions made in the person's best interest. Whilst this gives broad protection to care support staff it may be worth giving greater clarity to what constitutes a persons best interest again, to prevent potential conflict with service users relatives. Sources of conflict which do arise, particularly in the field of learning disability, are where care staff seek to maximise opportunities in the community which relatives do not see as relevant or appropriate. Examples of this would be the choice of holidays, pursuing educational opportunities or even expenditure on personal items such as clothes. Whilst the care provider may feel these opportunities are in the "best interests" of an individual (and can demonstrate this within a care plan) relatives may not feel this to be the case.

3.4 Care UK plc would respectfully suggest reference should be made within the draft Bill to a role for independent advocacy in determining what is in a "persons best interest".

3.5 Operationally, Care UK plc would also wish to highlight concerns it would have if consultees (as defined in 2(d)) are risk averse in their approach to care. This may result in users becoming more dependent on services. It may therefore be worth including a reference within the draft Bill that would see a person's best interests specifically linked to maintaining independence.

3.6 Furthermore, operationally within a residential or nursing setting, the care provider has a responsibility to protect the health and safety of all users and staff within a unit. The draft Bill does not currently reflect this. In theory at least, a decision could be made that is deemed to be in a person's best interest but which is contrary to protecting the health and safety of others. For example, it may be suggested that as a person has always smoked he/she should be allowed to do so whenever he/she so wishes. This may not be in the best interests of others if, resources do not permit appropriate support to facilitate this, within a residential unit and may lead to a fire hazard.

3.7 It is suggested therefore that the draft Bill needs to refer to the balance of acting in a person's best interest and the general health and safety of others.

4. THE GENERAL AUTHORITY

4.1 Care UK plc supports the view that the protection given to staff through the general authority clause will be a benefit that will enable daily decisions on behalf of service users, to be made with more confidence. What will be crucial in ensuring this general authority is used lawfully is ensuring all staff are appropriately trained.

4.2 To this end there may well be additional costs to delivering this training to all staff. In addition there may well be a need for greater guidance to be given within the code of practice for care staff that act under this authority.

4.3 Whilst supporting the general authority provision as it affects professional care support staff Care UK plc would wish to raise concerns about potential conflict that may arise in a residential care setting when others seek to act within the general authority powers. It would appear that there is no distinction made between a professional carer and other carers both of whom may believe they are acting in a person's best interest. Disputes could occur which it is assumed would need to be referred to the court for resolution.

4.4 Again Care UK plc would suggest that consideration should be given within the draft Bill to both the role independent advocacy could play here and to the establishment of a local arbitration process to resolve disputes before referring to court.

5. LASTING POWERS OF ATTORNEY

5.1 Care UK plc recognises the opportunity the introduction of Lasting Powers of Attorney (LPAs) gives to people, particularly with dementia to make plans for their future. It is arguable whether LPAs are applicable to people with a learning disability who may never have had capacity to confer decisions about their personal welfare, property and affairs.

5.2 Care UK plc welcomes the eligibility criteria and restrictions placed on donees of a lasting power of attorney. Operationally our concerns relating to LPAs would focus on where the donees may be considered to be abusing this power or where the requests of the LPA on behalf of the individual, are such that his/her needs cannot be met within the service provided. It is assumed that this would be avoided through regular care reviews involving the LPA but Care UK plc would be keen to avoid being caught in the middle of potential disputes between service commissioners (ie health and social services) and the LPA on this matter.

5.3 It may well also be worth within the draft Bill or code of conduct requiring the LPA to producing a written Power of Attorney plan. This could give general but clear directions as to welfare, property and affairs matters (including any advance decisions) and could be included in an individual's care plan. The production of such a plan would avoid confusion, and through regular review, would minimise abuse and ensure consistency.

6. GENERAL POWERS OF THE COURT

6.1 Care UK plc welcomes the establishment of the new Court of Protection and has no specific comments to make in addition to those made earlier about seeking local resolution to disputes.

7. ADVANCE DECISIONS

7.1 Care UK plc is aware that the inclusion of advance decisions in the draft Bill is widely supported but concurs with the view that effective implementation of this part of the draft Bill will require a public information strategy so that their purpose is clearly understood.

7.2 When implemented there will again be significant training requirements for care staff to ensure that advance decisions are lawfully implemented.

8. EXCLUDED DECISIONS

8.1 Care UK plc has no specific comments on excluded decisions.

9. MISCELLANEOUS AND SUPPLEMENTARY

9.1 Care UK plc would welcome the preparation of a code of practice to underpin the draft Bill. It is anticipated that the code would address some of the issues contained within the response and that it would also give clarity to care providers.

10. PARTS 2 AND 3 OF THE DRAFT BILL

10.1 Care UK plc has no specific comments to make on parts 2 and 3 of the Draft Bill.

11. CONCLUSIONS

11.1 Care UK plc welcomes the draft Bill and is grateful for the opportunity to comment on its content.

11.2 Whilst the Bill does give greater clarity and protection for all carers acting in the best interests of people without capacity, it is hoped that consideration will be given to the issues raised within this paper to prevent conflict and disagreements arising.

11.3 There will be practice and training issues that need to be addressed and resourced if the draft Bill is to be implemented successfully.

3 October 2003

39. Memorandum from Mr Simon Cramp (MIB 1179)

My Name is Simon Cramp, and I am a person with a mild Learning Disability. I am a trustee of two major charities—Royal Mencap Society, and a Housing Association called New Dimensions Group which through its operating companies provides housing to people with Learning Disabilities. I am also a Freelance Consultant working in the field of Advocacy and promoting people's rights. I am also involved in a lot of the work set out in Valuing People (Cm 5086, March 2001).

I will now set out from your terms of reference what I like about the Bill and where it can be improved.

The issues the Bill tackles have, of course, been discussed for a very long time. However, I believe the consultation process has fallen short of the ideal because a lot of people who could be affected by the Bill know nothing about it. Groups like Mencap and People First have done something to publicise the Draft Bill; but while I am a very involved part of these groups and I was aware that a Draft Bill was on its way, if I had been a member of say Joe Public I would have not possibly have picked this up. Learning Disability and other disabilities are still not news worthy or on the top of people's agenda. That is a pity when the Bill touches so closely on people's lives.

Are the objectives of the Draft Bill clear and appropriate? Yes, but I believe it was a good move on the Government's part to set up a Joint Committee; and hopefully the Government will find it useful in its future thinking.

What I like in the Bill, and where it can be improved: I believe the Government has drafted the Bill with good will, and tried to give it as much flexibility as possible. However, we hope for further listening to people with learning disabilities both in refining the Bill and in drawing up the Codes of Practice.

The Bill and the Codes between them need to make sure that:

- The priority is people being allowed to make their own decisions.
- There is encouragement of listening to people who don't use words but can communicate by other means.
- People who need help in making or stating their decisions have the support of independent advocacy and circles of support.
- Supporters for people are those who know them well and are chosen by them—supporters they are comfortable with.
- Disabled people and others with decision-making problems are allowed time to make decisions with support, rather than being rushed into someone else's decisions.
- Where urgent decisions have to be made—for example there is a life-threatening condition to deal with—there is still hard listening to the person himself or herself and to those who know them well, including the doctor in medical cases.

The Code could usefully take as an example of an important decision that is not urgent the decisions needed around a holiday for a severely disabled person. Another more significant example would be where someone lives (in cases where the person can not simply decide that for themselves).

I welcome the safeguards in the Bill to protect vulnerable people from abuse of their affairs, but I think there need to be rights of appeal against assumptions being made that they are not able to make decisions, and against decisions made by others that seem to be abusive. The Bill as it stands does not encourage independent advocacy by individuals or by circles of support—in vetting decisions about competence, in vetting decision making by alternative decision makers, and in supporting appeals.

We have lost in this draft the obligation of Social Services Departments to protect vulnerable people where their interests are being threatened.

I hope these points will be useful to the Committee and to the Bill.

August 2003

Witnesses: **Dr Maurice Brook, Mrs Mary Pearson, Mr David Sugden, RESCARE; Mr James Allen, Care UK, and Mr Simon Cramp, New Dimensions Group and MENCAP, examined.**

Q672 Chairman: Thank you all for coming. You heard all the housekeeping notices at the beginning so I will not repeat them. We are not preparing a White Paper on mental incapacity; we are working on a Draft Bill and that is why the questions you have seen have been structured around the structure of the Bill. Would you like to introduce yourselves?

Mr Allen: My name is James Allen. I am the development director with Care UK. We provide residential and nursing care for people with mental health problems and disabilities.

Mr Cramp: Simon Cramp. I am a trustee of MENCAP and a member of New Dimensions. I am also an independent consultant.

Mrs Pearson: I am Mary Pearson. I am with RESCARE and I am the mother of a 23 year old daughter with Downs Syndrome.

Dr Brook: I am Maurice Brook. I have a 51 year old severely mentally handicapped son, mental age around 3 years. I am a joint honorary vice-chairman of RESCARE. I am also a receiver in the Court of Protection for a severely mentally handicapped man who is not a relative.

Mr Sugden: David Sugden, a joint honorary vice-chairman of RESCARE and I have a handicapped daughter who is 35 years old and being very well looked after, thank you.

Q673 Baroness Wilkins: What do you not like about the Draft Bill?

Dr Brook: Very little. We like the framework it sets. If you push us to say what we do not like, I suppose we are echoing what was said earlier, but we have a certain amount of unease about a recognition that those who are mentally incapacitated from birth, or virtually from birth, have some needs that are different to the majority of people covered by the Bill who have long periods of perfectly normal capacity. That can be dealt with in the codes of practice.

Q674 Baroness Wilkins: That is how you would like to deal with it?

Mr Cramp: I would like to thank the Committee for inviting us here today. I welcome the opportunity to speak as someone who supports the Bill and necessarily supports decision making and encouraging good communication in advocacy and human rights. If I were making decisions for somebody who could not do it for themselves, I would expect to be held to account. My main point is that we desperately need this Bill and I feel

passionately that it is not an opportunity to be missed. Some organisations think that if the Bill were to become law it would take away more decision making powers for people. I feel this is not the intention of the Bill. There is a possibility in practice that this might be an outcome for some people but there is the general authority as a provision. At the moment, the general authority to act is too wide. Carers can decide almost anything without having to take formal authority. It is too difficult for someone who feels that their wishes have not been listened to to challenge decisions taken by someone else. I do not like the name of the Bill. It should be changed to "the Mental Capacity Bill" to reinforce the idea that it gives people the right to make their own decisions. I do not like the fact that independent advocacy is not included on the face of the Bill because it is putting people in jeopardy. Thank you.

Mr Allen: As a provider of residential nursing, I have four issues. There is the issue about conflict resolution. There is not enough emphasis in the Bill about the delays there might be about the resolution of conflict between various policies. There are concerns about maintaining independence. That is key to everything we do, providing care for people with mental needs. We have some issues about how to provide care that represents the best interests of individuals in a residential setting, because we have to consider the health and safety implications of a range of people within our settings. There is also an issue about advocacy which is not mentioned in the Bill. We feel that some conflicts can be avoided and resolved through advocacy.

Q675 Baroness Knight of Collingtree: Some, if not all of you, were here in the previous session and you will have heard what was said about the general authority part of the Bill. I would like to ask what you think about this. Particularly, would you tell us about any problems that you think might occur because of the general authority? There was clearly very strong feeling among those who have just given evidence and they did make some suggestions. All of us would like to hear your comments on what they had to say and what you feel about this.

Dr Brook: There was some misunderstanding about the nature of the general authority in the implication that it would be vested in an individual, whereas our interpretation of the Bill is that this is dealing with day to day decision making by any person who is

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delivering care. There could be many people involved. It is regularising for their benefit the position which obtains now in common law. We do not see the general authority as a danger, providing the person is committed to assessing whether the individual has the capacity to make a particular decision before they exercise this general authority. They will then be answerable afterwards and have to explain what their reasoning was in reaching that decision. We do not see any problem in the application of the general authority. We think it should be welcomed, certainly by paid carers who are sometimes in an anomalous position.

Mrs Pearson: I think it is important also to realise that we represent the families of people who have a severe learning disability, life long very often. The people we heard earlier have, as far as I could see, a lot of capacity. It is understandable that they could feel threatened by this Bill but, for the people we represent, I do not think that is the case.

Q676 Baroness Knight of Collingtree: You seemed to give the impression that once a person was defined as being incapable of making their decisions that was a permanent thing. Is that the case or not?

Dr Brook: As the Bill makes plain, it refers to a particular decision in a particular situation. For example, someone wanting to go out when it is raining inadequately clothed. A carer would very properly under the general authority make sure that they had protective clothing on before they went out. The individual might appear to be resistant to it.

Q677 Baroness Knight of Collingtree: That was not quite the point I was making. I just wanted to know whether you felt that, once a decision that a person was incapable of making decisions about his own life was agreed, that could never be gone back on.

Mrs Pearson: There is a reality about whether people can make a decision.

Q678 Baroness Knight of Collingtree: I appreciate that we are dealing here with more severe difficulties and that may be the basis of the comments made earlier.

Dr Brook: There is a range of incapacity from those who are virtually able only to be fed and give very little response to anything to those who can indicate a number of decisions. You do not classify an individual at any stage in the process, other than by having reference to their behaviour and their apparent needs. We do not have a legal system any more like we used to for classifying people ineducable or not, for example.

Q679 Baroness Knight of Collingtree: Do you think the suggestions made, for instance, about the possibility of a person complaining and the difficulty under the law of that happening are a problem or not?

Dr Brook: I do not think that is something the Bill is here to address. Most organisations now have proper complaints procedures. If an individual is having difficulty in gaining access to the complaints procedure, there are other ways of dealing with it.

Mr Cramp: I would slightly disagree with my colleagues about complaints because of access. Not everybody can reach the papers you have in front of you. There are communication difficulties. You could have a situation where somebody has not made suitable provision for complaints. That is the first problem. If I can come to the question of the general authority, I have the difficulty that it almost allows you to do anything.

The Committee suspended for a division

Q680 Baroness McIntosh of Hudnall: It has been put to us by other witnesses that this Bill as currently drafted is potentially more of a charter for carers and service providers than it is a protection for people who may lack capacity to make decisions. Do you have a view about that? Can you tell us from your experience how it would be best for people with incapacity to be informed about what the Draft Bill could do for them?

Mr Allen: It certainly offers protection for carers which we are grateful for because it gives clarity about working in best interests. However, as a provider of care, we are regulated and monitored by National Care Standards and other organisations. There are regulatory bodies ensuring that we are fulfilling our obligations satisfactorily. In addition, we are monitored through care contracts and specifications to ensure that we deliver care appropriately. If there were to be an abuse of the carer's authority, that would be easily picked up through the monitoring that takes place.

Q681 Baroness McIntosh of Hudnall: It would be fair to say, would it not, that that applies to you because you provide your care in a formal setting? There are many carers who are not subject to that kind of monitoring.

Mr Allen: Certainly. I am talking about professional carers.

Q682 Baroness McIntosh of Hudnall: That is who you are here to represent. It is slightly unfair to put you on the spot about those people who do not do what you do but do you have any view about the Bill in general in relation to the authority perhaps that it gives to people who are not regulated in the way that you are?

Mr Allen: I think the Bill is fairly clear about what is and what is not permissible. Also, in terms of best interest, I think it is quite clear. Also, the additional assessment of the current protection gives a quite clear framework in my mind as to what is and is not acceptable.

Q683 Lord Rix: Do you think, on the other hand, that this Bill erodes the protective powers which we parents seem naturally to assume for our children? They will of course go on to adulthood. Should our protective powers then be diminished?

Dr Brook: On the contrary. We feel that our protective powers have been substantially eroded or are absent, once our children reach the age of formal majority. The Bill would help us. That is one reason

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why we need it. We think there is a need to make a distinction between family carers who are unpaid—and they are the only ones who maintain a continuous interest and concern in an individual throughout life, giving unconditional love and affection—and care workers who are paid and who change frequently.

Mr Cramp: In the Bill, if it was possible, I would want to make it separate, where paid carers are separated from family carers. The state saves quite a lot because of parents who are unpaid carers but in terms of the question of abuse, if you work for an organisation and you abuse anything, you will be subject to some form of discipline. With a carer it is more difficult. There is no formal power and we strongly recommend that there is some kind of distinction between them.

Q684 Baroness McIntosh of Hudnall: We did not get an answer to the second part of the question and I think it would be helpful if you could comment. Perhaps I can put it slightly differently. Can you comment on your responsibility within either a formal or an informal framework to ensure that the people to whom you provide care understand their rights and the protection that is offered to them by the Bill? Do you see yourselves as having a direct responsibility to interpret or ensure that the law is communicated or that the provisions of the Bill are communicated?

Mr Allen: Yes. We would have a responsibility to ensure that people were fully aware of their rights under the Bill.

Mr Sugden: From a parental point of view, there are going to be several occasions where the severely incapacitated will not understand anyway. There are degrees of this. Obviously one tries. Parents get more difficulties throughout the lives of these folk anyway. This is not a difficulty in my particular view or my wife's view, I am quite sure, because one naturally does this, but there are going to be some who simply will not understand, full stop. It cannot be helped.

Q685 Mrs Browning: Simon Cramp was asking for us to try and define on the face of the Bill between the paid carer and the voluntary carer, usually a close family relative. In what context do you want us to make this distinction?

Mr Cramp: If my parents were looking after me, I would want to make them unpaid carers. In a previous life, I used to work for social services, so that is where I see the paid carers. In terms of advocacy, there is a line where you get advocacy for the person. There are procedures, whatever the organisation or whatever is in parliamentary law, which are set in and they restrict what you can do. There is more of a legal footing if you abuse somebody in any criminal way. It is easy to go through the court system where family carers would find that perhaps more difficult.

Q686 Mrs Browning: Empowerment and the rights of individuals on the face of this Bill are the purpose of this Bill but in some cases the decisions which individuals wish to make may conflict with the

wishes of the family carers and the care workers. Do you think the Bill makes sufficient provision for the resolution of such conflict and that people are enlightened in this area?

Dr Brook: A Bill like this and the codes of practice which accompany it is only going to begin the process of changing the whole climate of opinion and behaviour by all those concerned. It is not realistic to expect such a change to happen overnight, even if the Bill became an Act, but we would expect over time that in some cases through case law, established by reference to the Court of Protection, and in other cases through informal advice which we hope the Court will be able to give, as the Court of Protection has done in the past on financial matters, you begin to influence the climate of opinion making and behaviour. Some guidance on assessing the reliability of decision making by a person with a particular degree of incapacity is going to be necessary and we have some views on that too.

Q687 Mrs Browning: There is nothing on the face of the Bill about independent advocacy and a lot of witnesses have pressed us to consider including this in the Bill. What happens when you have a difference of opinion between the independent advocate and the carer closer to the person, perhaps the parent?

Dr Brook: We are assuming straight away that there will be an independent advocate.

Q688 Mrs Browning: I am saying if we were to incorporate that within the Bill.

Dr Brook: There are some considerations there. This is why there is recourse to the Court of Protection. There will be an earlier stage where one can get informal advice. The existence of the Court of Protection and the opportunity to go there to resolve disputes or to get a ruling which will establish case law is important. There will be some occasions when there is clear disagreement. Very often, they are about simple day to day matters and these need more independent discussion between the person who really is the decision maker and the person wanting to provide a service. It is a fallacy to imagine that a so-called independent advocate can come into any situation and very quickly become appraised of all the implications of the decision and almost make an adjudication. I as a receiver have been in a situation of having an advocate appointed by the local authority because they were in disagreement with my view about the provision that should be made for a person. I have known this person for 20 years. This person has no speech and a very low mental age. The advocate was totally at sea. In the end, what I wanted was brought about. Afterwards, it was agreed that it was the right decision. Had I not had the knowledge and authority to stand up to the advocate, the advocate would have endorsed what the local authority wanted, which I discovered afterwards was placement in a residential home where they had a block contract and a vacancy, regardless of suitability for the individual. This is a practical situation that occurs all the time.

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Mr Cramp: I would agree to some extent but there is an element of risk with all this. Everybody is human. If we all looked like robots it would be a very worrying thing. We all make mistakes. As the Bill is drafted, perhaps there could be letters about complaints, perhaps some kind of panel that is accessible locally, made up of a lay person and someone from social services. I agree with my colleagues to some extent but if the independent advocate makes a mistake there should be some kind of mechanism to help that process through so that it is then transparent. There is no way that the person who makes the complaint is always going to have it upheld.

Q689 Mrs Humble: I want to raise the point again about defining what we mean by advocacy services. An independent advocate is usually a volunteer who has been trained by the local advocacy service. It is not an adjudicator. The advocate is the voice of the individual. Dr Brook, you raised an interesting point because you seem to be saying that for certain individuals who are profoundly handicapped their level of capacity or lack of capacity is such that they may not be able to communicate to that advocate. You used the phrase, "The advocate was all at sea."

Dr Brook: Yes.

Q690 Mrs Humble: How can we address the concerns raised with us by our previous witnesses that, for many people, even with very profound handicaps, if an effort is made to try and open lines of communication, they can act as the voice of that individual?

Dr Brook: I would challenge a good deal of that argument. The ability of severely handicapped people is limited obviously by their own intelligence. My son, mental age three; actual age 51, can clearly indicate decisions on what you might call immediate gratification: what he might want to eat; what he might want to put on for clothing, even though he might not get it on the right way round. We have known him for 50 odd years and it has taken a long time to understand some of his signals. There is no way in which a person coming in from outside would accumulate that ability to interpret his noises and signals and his happiness to be able to say with confidence that that is what he is choosing to do. The people who work with him have never worked with him for long periods of time because care staff are constantly changing. They would know him better even than bringing in someone from outside. The phrase "independent advocate" needs closer examination because most of the advocacy services are totally dependent on public funding. In my area, we have quite a lot to do with them. More often than not, they are influenced by what the authorities are wanting at any particular time. They are not closely associated with an individual. Citizen advocates, when first introduced, were aiming to do that. We had on our committee the longest serving citizen advocate in this country but there has been a very high turnover. It has taken her 14 years or so to get to know the person for whom she now advocates very effectively.

Q691 Mrs Humble: Given the caveats that you have outlined from your own personal experience about profoundly handicapped people, given your own experience of your own local advocacy service, which is not my experience of my local advocacy service, do you think there should be provision for advocacy services on the face of the Bill? If that is the case, how can we monitor the delivery of those services and look at the quality of those services, bearing in mind that advocacy services will be providing support and a voice for people not as profoundly handicapped as your child, people with variable handicaps and within the context of the whole of the provision of this Bill?

Dr Brook: Where people recognise the need to be assisted in expressing their needs or their point of view, yes, there is a need for this kind of service. We have to remember too that many people who are in regular contact with people with disabilities are in particular situations very much acting as their advocates. They do find out what they want and they do press the point. These can be teachers, nurses or psychiatrists. It is wrong to assume they are not doing that, although they may not use the term "advocate". When you come to having people acting independently as advocates, considerations of cost and availability become important. There are some important calculations that I have done for my local advocacy service which is multiplied nationally, implying tens of millions of pounds to deliver what is even now not a very adequate service.

Q692 Mrs Humble: Are you saying that you would not want us to argue for one?

Dr Brook: The codes of practice can deal with the recognition that some people will wish to have—and indeed some parents will wish to have—some assistance in expressing their point of view and it can come from a variety of sources. Any one of the sources that is acceptable should be recognised as expressing that person's point of view. To include in the Bill the right to a service and commit the government to providing one will be a very foolish move because it would not happen; you would not get the money and you would not get sufficient individuals. Even in areas where there is a service, you find that one advocate is acting for many different individuals. Citizen advocacy, the one to one service, is relatively rare compared with the other sort. They all call themselves independent advocates. When we look at the programmes and the sources of finance, it is difficult to accept that they are really independent. The voluntary bodies can do quite a lot. The charities can do quite a lot but trying to turn it into a national service I think will fail. It will absorb a lot of start-up money and government money in the interval before it is finally recognised.

Q693 Mrs Humble: Does everybody agree with Dr Brook or disagree?

Mr Cramp: I disagree. When *Valuing People* was published two years ago, I think about 400 people benefited. While I agree that there are some concerns, if it does not work out quite as we would like it, it does not mean to say it should be on the face

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of the Bill. I say that not just from the learning disability point of view but from the point of view of all disabilities. We all need some kind of advocate or some help at some point in our lives.

Q694 Chairman: Are you suggesting that the need for advocacy should be in the code of practice because that is much more flexible?

Dr Brook: Yes.

Mr Sugden: Either on the face of it or in the codes of practice but—and here is a big “but”—we have to have the family to be consulted there because something like 60 or 70% of the sort of people we are dealing with at our end are looked after by the family anyway, which is frightfully important, and therefore we may need a definition of family carer. We may need a definition of volunteer carer, paid carer and advocate. As Dr Brook says, advocates come in many shapes and sizes, including paid.

Q695 Lord Rix: Would you care to offer any figures, actual numbers?

Mr Sugden: Of, sorry?

Q696 Lord Rix: Of people who might require advocates? Have you any idea how many?

Mr Sugden: I would be plucking figures out of the sky. Come on, Maurice, help me.

Q697 Lord Rix: Dr Brook did quote facts.

Dr Brook: That is a good question. Some of the people speaking this afternoon are probably in the category of mild to moderate handicap of which we have about one million in the country. We have about 175,000 severely profoundly handicapped. To put this into context, in my area in Surrey, we have advocacy partners who I believe may have given evidence to this Committee. From their last annual report it is possible to work out that they are giving a service perhaps to 510 people out of a handicapped population of about 40,000. The cost of that service seems to be about £780 per person, of which 80% is coming now from public funds. Now they may be able to contradict these figures and have different figures but I can only take my calculation from their annual report. Your experience in Blackpool might shed some light on this because I do think we have to be hard headed about any proposals of this kind. Just to multiply that service which, as I say, is only now touching a small proportion of the people in the area, to say 100,000 people nationally, which is under 10 per cent of those available, will require £78 million, of which £62 million will come from the public purse if they continue to be funded at the present rate. Now I can think of much better ways of spending £60 million in services to this group of people than that way and there are other ways of approaching it I think.

Q698 Laura Moffatt: Chairman, it is obvious that caring parents—as has been demonstrated around this table both by those who are asking questions and those who are answering—will fight like alley cats for their children and that does not matter if you do not like the girlfriend your son has brought home

or if you are having to look after someone with profound learning disabilities and making day to day decisions for them, so that is a given. The problem that this Bill faces is that not everyone with either a learning disability or someone who suffers temporary incapacity or develops an incapacity has that sort of care. Now this Bill has to deal with that. It is incredibly important to hear from parents their view but we have to find a way for the Bill to deal with that. We have to find some middle ground where the parents feel secure in the fact that there may be different people who can assist with decision making, there may be those who can add to that process and give value to that process. Can you tell me if you feel that there is any middle ground for you or if you believe firmly that there is no value?

Dr Brook: There is value in particular situations, as I think I said earlier, but it is a limited application and what seems to be being proposed will be advocates who would operate alongside parents, for example, particularly in cases of dispute. You cannot have a situation in which you have more than one decision maker.

Q699 Laura Moffatt: You can have partnership in decision making?

Dr Brook: Yes, indeed, but at the end of the day one person is taking the responsibility and it has to be the people who have to live long term with the consequences.

Q700 Mrs Humble: The advocate is not the decision maker, the advocate is the voice of the person who is at the centre of the discussion. It happens now that the advocacy services engage with families where the view of the parents, may be about the future care of an adult child in a household, is at variance with the views of that adult child and so the advocacy service gets involved but as the voice of that person so that voice is heard. I have met individuals in these circumstances where they feel reluctant to argue against their parents, because they care about their parents and they do not want to upset them, but they also feel very strongly that they have a different perspective and what they want is that perspective to be heard. At the end of the day the decision will be made by the professional taking into account the views of that individual and if that voice is then handled by the advocacy services so be it but we should take into account the views of the individual and the views of the parents. Like Laura has been saying can we look at this draft legislation to make sure that the voice of the individual is heard and is heard directly wherever that is possible or indirectly through an independent voice plus the concerns of carers and professionals so all the people involved can be heard. How can we frame that in the legislation?

Mr Sugden: It has got to be codes of practice, has it not, surely? Certainly the Bill as it stands is absolutely first class, that is a personal view. Codes of practice: that is where the nitty gritty has got to be really ground out, that is the way personally I see it. We have to tackle these different things. What is more it is quite possible there is a different code of

21 October 2003 Dr Maurice Brook, Mrs Mary Pearson, Mr David Sugden, Mr James Allen and Mr Simon Cramp

practice—this is me talking not RESCARE—for the grouping that we happen to be involved with compared with, let us say, those with Alzheimer's disease or whatever it might be, who have been perfectly okay in the past.

Mrs Pearson: May I just say I think there can be a real problem in finding the voice of the person. I have had this experience myself and I know many people who have as well. My daughter is at the upper end of ability, if you like. She does not have legal capacity but she is perfectly articulate and she is plausible and she is able to make day to day decisions and be very definite about what she wants, and obviously we encourage that but she is very suggestible, she is very vulnerable and she wants to please whoever talks to her. It depends entirely how you put the question how she will respond. If you have an advocate who has an axe to grind to the extent that they might be employed by the authority—we have been through this mill ourselves so I know—if you as the family have a dispute, not with your child but with the authority and the authority then comes in with their advocate, independent perhaps but only slightly independent, you then have a problem that there can be pressure put on that very vulnerable person. In a sense there is a conflict that is not really a conflict with the person at the centre, the conflict is between what the family believes to be the right course and the best course for their vulnerable relative and the authority who has a different agenda. Do you see what I mean?

Q701 Mrs Humble: Yes, I see what you mean. It goes back to a question that I asked Dr Brook earlier about if we were to proceed along the lines of suggesting that an advocacy service is very important for the successful implementation of this proposed legislation, then it is the issue of how that is defined, monitored, supervised?

Mrs Pearson: It is so subtle. This is what is difficult. It is so subtle. The people who were speaking in the first session, I am sure that with the majority of the people they represent there would not be a problem, they would need encouragement, support and perhaps help reading things and understanding. It is a completely different ball game from what we are talking about. Even my daughter who, as I say, if she was sitting here, she would be very well behaved, she would listen, she might even pitch in on one or two points but she would not have the foggiest idea what we were talking about and she would not understand the consequences of any decision she made. It is another way of communicating with the person and an advocate, somebody from outside, with the best will in the world will have a job to discover what her

real wishes and views are. Even those change from day to day, month to month, year to year because she cannot weigh up things in the balance and she cannot understand the consequences. Only people who know her very well and consistently and observe her minutely—when I say “her” I am talking about many other people like her who I know also—only someone who has that knowledge is going to be able to pick up the signs really and help her to identify what she wants. You cannot do that if you come in and see a person half a dozen times.

Q702 Mrs Browning: Very quickly to pick up on that point and also to pick up a point that Joan Humble made. You said in your response then it will be the professional who will decide. Parents spend their lives battling the so-called professionals.

Dr Brook: I quite agree with you.

Q703 Mrs Browning: Whether they are social services who have not got the resources and try and fob you off with something totally inappropriate or whether it is psychiatrists who really do not know one condition from the next but think they do. We had an admission of that when we questioned the psychiatrists. I just have to say to the parents here I think the point you have made, and the point Mary Pearson has just made, struck home because where I am very concerned, Chairman, and we have put this question to various witnesses, is where the balance falls. I am in favour of the principle of independent advocacy but when somebody has to go that extra mile to take on and challenge the so-called professionals it is not going to be an independent advocate who is going to run with it.

Mr Cramp: That comes back to the point I was making about the appeal system. One thing I strongly believe and I understand about independent advocacy, they can be the best people and they can be the bad people but I think if you have the option and put it in the Bill, either the Bill itself or the code of practice, that person chooses who they are then I think you go some way to that. Also I think you can still challenge it through the court protection if that system is set up but again it comes down to resources and it depends who is committed to doing that.

Chairman: I think there are two large areas which we have not got time to consider properly, assessment of incapacity and best interest. If you would kindly write to us on those areas that would be helpful. We have had a useful discussion. We have spent a long time on advocacy which is so important in your circumstances and of course in the circumstances of the first group. It has been a very useful afternoon I can assure you. Thank you.

40. Supplementary memorandum from RESCARE (MIB 1217)

The Committee asked our witnesses at the 21 October session to submit further comments in writing. Assessment of capacity and best interests were named by the Chairman and a response to the questions which time did not allow. We thank the Committee for the opportunity to be questioned and for the courtesy and understanding afforded our delegation comprising of Dr Maurice Brook, Mr David Sugden and Mrs Mary Pearson. We further comment as follows:

Assessment of Capacity: The Draft Bill needs to say no more about assessment of capacity procedure as changes in technology, knowledge and experience make this particularly appropriate for guidelines in a Code of Practice.

In most day-to-day situations a person in a caring role must necessarily make assumptions about capacity. The more knowledge they have of the individual in different situations the more reliable will be their assessment in relation to any particular decision. Before waiving an apparent decision signalled by a handicapped person the person providing care must believe that the 'incapacitated' individual has failed to consider obvious risks and possible adverse consequences and cannot be helped to overcome their own lack of understanding. The incentive of offering an alternative course of action that satisfies is a diversionary technique acquired by many parents through experience in day to day management.

RESCARE is concerned with people whose IQ is below that of over 98 per cent of the general population. It has especial concern for the many, ie. tens of thousands who mentally remain infants and young children. Although IQ alone is not always an adequate predictor of capacity it has an important bearing on it, particularly on capacity to assess and understand the consequences of decisions.

Some vulnerable individuals will appear to agree with suggestions made by someone they see as in authority, or someone they want to please. They say convincingly whatever they believe their particular interrogator wants to hear. RESCARE frequently encounters situations where social workers have taken a handicapped individual aside, emerging later with the claim that the individual wants to do this or that: for example to live where the authorities happen to have a vacancy they want to fill. Even, sometimes, RESCARE has met claims that the handicapped person has decided that they want nothing more to do with their family, after many years of apparently harmonious and loving relationships.

We should record the fact that many of those for whom we have concern never have and never will exercise the fundamental right of a citizen to vote in an election. They can be on the electoral register, but it will be obvious to the polling clerk that they have no understanding or awareness of the process and therefore may not be allowed to proceed. This is an example of a lay person necessarily assessing mental capacity. In practice, of course, they are not taken to vote.

Pragmatically, we think that elaborate, inadequately tested procedures of assessing capacity must be eschewed except perhaps when there is serious disagreement about an individual that affects important decisions. In reality, carers will rely largely on commonsense, tempered by experience and training. For 'life-important decisions' appointed Deputies will have an authority related to an earlier assessment of capacity.

'Best Interests': The term 'Best Interests' covers all contingencies while 'Maintaining Independence' is related to the extent of disability and multiplicity of needs to be met. We are concerned with the thousands of individuals who are already highly dependent.

Assistance to help the individual to make an informed decision, where practicable, is important. This process could require expert effort, detailed knowledge of the person and take time.

Some life-important decisions, such as where to live, health, medical and dental requirements, are particularly critical. 'Best interests' long-term may not be perceived by the individual (or some others) as in their best interests short-term. A practical example is that of an elderly mother who has cared at home for a severely handicapped daughter, herself now in her 50's. Mother, advised by her doctor that her health is failing, finds a residential home which she thinks would be congenial for her daughter and offer life-long security.

Daughter enjoys several visits and an overnight stay but clearly has no appreciation of what it will mean to leave her mother, except for visits. Daughter is moved and not surprisingly is bewildered and miserable at first. In time, fortunately, she becomes noticeably happier although sad and tearful when each visit home comes to an end.

Decisions about medical and dental treatment can be especially tricky when the handicapped person vigorously signals objection to a procedure that is necessary in their 'best interests' even though it may not be to deal with an immediate, life threatening situation.

This term seems to us to be sufficiently widely used generally, and, in English law and medical practice for it to be undesirable to create inconsistency by modifying the term or substituting another, such as 'personal benefit'. Of course, a Code of Practice will be necessary to provide guidance on what is important in determining someone's best interests. We hope and expect to be directly involved in the drafting of Codes of Practice in respect of those for whom we are most concerned and with whom we have direct experience, bearing in mind that over 70% of them live within their own families.

We would like to add other comments that may be helpful to the Committee including response to questions not considered.

Appointment of Deputies: We welcome this opportunity in the Bill with the intention that there could be joint deputies; two parents, one parent and a sibling, two siblings etc. We are sure that many families will want to become deputies as a means of establishing their legal rights and responsibilities as substitute decision makers for those of their relatives who clearly lack decision making capacity in relation to important aspects of their lives; where to live for example, or what medical and dental treatment to have. At present, the Bill takes inadequate account of the views of the Law Commission. They envisaged that 'Managers' (now 'Deputies') would normally be a family member. For those incapacitated from birth, whose mental age remains that of a young child, our members feel strongly that their role must be recognised in law by endorsing the desirability of them becoming deputies to act when appropriate as substitute decision makers. This could be done in a Code of Practice.

In connection with deputies, our witnesses strongly disagreed with the committee member who expressed the opinion that, eventually the 'professional's' would make the final decision. It is to avoid precisely this that RESCARE has been lobbying for legislation for some 15 years. In brief, the professionals should be advisors and persuaders. Decisions should be made by the individual, when they have adequate capacity, or by an identifiable substitute ie—a Deputy. If there is a real concern among the professionals/authorities, or indeed within a family, that the wrong decision is being made then recourse to the advisory or other more legal services of the reconstituted Court of Protection will be available.

Extended Minority: The concept of Extended Minority arose in the late 1970's, from a working party of The Law Society. In essence, regard is given to mental age. Those of much reduced mental age would continue to be treated as minors, with parental rights and responsibilities being continued with ongoing protection beyond the chronological age of majority. This simple concept appeals to some of our members, especially if their relative is profoundly handicapped. The opportunity offered by the Bill to occupy the role of deputy is a satisfactory and more flexible way of dealing with the problem for parents and relatives. However, regard to damaged intelligence and substantially reduced mental age should be incorporated in a Code of Practice, giving guidance about decision making.

Advocacy: We assume that the Committee will not seriously entertain the suggestion made by other witnesses earlier on the 21, that parents/relatives should not be advocates. This is precisely the role most of them have fulfilled for years. Any attempt to exclude them will cause much disruption and will fail.

Taking account of 'the expertise' of the caring family: We recognise that many adults with mental illness and mentally incapacitated elderly people wish to avoid family involvement. However for those with life-long incapacity, committed family members are the only people who maintain a concern for their welfare throughout life and who thereby acquire a unique longitudinal knowledge of their needs, preferences etc. Moreover, they are invariably called upon by the statutory authorities to sort out difficulties or provide support: for example if their relative is admitted to hospital for treatment. This happens even when the statutory authorities have previously kept the family members at arm's length.

Scale of Costs: This will presumably include the Bill and any Code of Practice Guidance. The voluntary sector could well play an important role and we expect those charities, such as ours, in direct contact with their members to disseminate information as a welfare service at modest or no charge to public funds.

Do we like the Bill: Yes. For the first time ever the long awaited Bill offers protection for people with a life long incapacity and recognises the need for Deputies (Substitute Decision Makers). It ensures a minimum of bureaucratic intervention with the application of common sense.

The Bill's ultimate and important potential is to progressively and drastically reduce the areas of costly confrontation and increase mutual respect. That can only be good.

Our members wish fervently to have legislation along the lines of this Bill quickly.

October 2003

41. Supplementary memorandum from Mr Simon Cramp (MIB 1214)

Thank you for giving me the opportunity to speak at the oral evidence session of the Joint Committee on Tuesday, 21 October. I hope the Committee found my evidence useful. You asked me to provide written answers to appropriate questions which we did not have the opportunity to talk about in the session and to say more, where I could, on anything the Committee asked me about. I would like to comment further on the General Authority to Act, the Court of Protection, the need for independent advocacy and how to make the final Bill more accessible.

1. THE GENERAL AUTHORITY TO ACT

The General Authority as it is currently set out would allow almost anyone to do almost anything. I think the scope of this power and the types of decisions which should be made under it needs to be tightened.

People with a learning disability are very fearful of the wording "reasonably believes" and it should be changed. It needs to be clear in the Bill that if someone wants to make decisions on someone else's behalf, they would have to go through a number of tests to ensure that the person could not make the decision themselves.

A distinction should also be drawn between paid and unpaid carers. It would be a safer power if paid staff had to work to a person-centred plan and keep records so that they were accountable for the decisions they made. I recognise this is not practical for family members to do on a day-to-day basis but they should have to ask for formal powers if they wanted to take big decisions such where a person should live when they leave home.

I do not think we should rule out the whole Bill on the basis that the General Authority part needs changing. The system we have at the moment is not acceptable to people with a learning disability and should be changed.

2. INDEPENDENT ADVOCATES

I don't think the draft Bill makes sufficient provision for the resolution of conflicts between carers and people who have difficulty making or communicating a decision.

It needs to be made clearer in the final Bill that people should be allowed to make their own decisions. Putting the principles at the start of the Bill would help.

But people who have difficulties making decisions also need to be able to access support from independent advocates when making big decisions. An independent advocate should be there to ensure the voice of the person with a learning disability is heard rather than as an alternative decision-maker. Wherever possible, this advocate should be of the person's choosing. Independent advocacy services should follow a national code of practice.

I would ask the Committee to please mention the need for advocacy in their report as people with a learning disability really do need it on the face of the Bill as a safeguard against having decisions made for them by someone else.

3. COURT OF PROTECTION

The Court of Protection needs to be accessible for people with a learning disability to challenge decisions made on their behalf. One way of making it more accessible would be to have a panel sitting at a regional level—perhaps made up of a mix of professions such as a lawyer, a parent and a social worker—which conducts its proceedings in a way that a person with a learning disability can understand so that going to Court is not so scary. The people from the Court will need to be trained properly on how to deal with people with a learning disability.

4. INFORMING PEOPLE WITH A LEARNING DISABILITY ABOUT THE BILL

People with a learning disability have not been well informed about the draft Bill and that is one of the reasons why they are so angry about it. It was really good to have an accessible version of the draft Bill but it wasn't as accessible as it should have been and didn't tell the whole story. We will need a proper accessible version of the final Bill and accessible documents, like the code of practice, when implementing the Bill. I think the Government should ask people with a learning disability to help write these. A steering group could be set up to advise the Government.

The Government will also need to work with organisations like Mencap and others to consult and inform their members.

Thank you again for asking me to give evidence and I hope I have been able to provide some insight into how people with a learning disability feel about the draft Bill and what we would like changed. If I can be of any further assistance or you would like me to clarify any of the issues I've talked about, please do not hesitate to contact me.

Simon Cramp

Wednesday 22 October 2003

Members present:

Barker, B.
Carter, L. (Chairman)
Fookes, B.
Knight of Collingtree, B.
McIntosh of Hudnall, B.
Pearson of Rannoch, L.
Rix, L.
Wilkins, B.

Mr John Bercow
Mrs Angela Browning
Mrs Joan Humble
Huw Irranca-Davies
Laura Moffat

42. Memorandum from the Department for Constitutional Affairs (MIB 1223)

The purpose of this document is to provide a broad outline of the general principles and considerations that will influence the content of the practice codes and guidance. Future consultation with stakeholders will examine these and will inform the final Code of Practice. The information given is based on the position in October 2003.

1. GENERAL PRINCIPLES

Broad principles on which code of practice is based which people should follow. Examples given in all cases

- How lack of capacity relates to each decision to be taken.
- Temporary and permanent capacity; periods of lucidity
- Inability to make decisions what are the factors to be considered? What are all the “practicable steps” that should be taken? Give examples.
- Best interests—underlining that it is the person’s best interests, not what others think these are
- Informal decision-making—general authority to act—to underline that this follows consideration of capacity for a particular decision; the conclusion that someone is not capable for that particular decision; and the consideration of the person’s best interests and their involvement/participation in the decision-making process
- Formal decision-making powers—LPAs and court appointed deputies—to spell out the sorts of factors people need to consider in choosing one or more attorneys and the seriousness of the decision to appoint one; also to emphasise that the appointment of deputies would be considered only if single Court orders were not appropriate and that deputies’ powers would be as limited as possible.
- The new Court of Protection—its role as an arbiter of last resort
- The new Office of the Public Guardian—what it will and will not do and how it will relate to other organisations
- The new criminal offences
- Admissibility of this code in civil and criminal proceedings and effect on court proceedings generally
- Duty of person to this code if acting in a professional capacity or for remuneration in relation to a person lacking capacity

2. ASSESSING CAPACITY AND SUPPORTING PEOPLE TO MAKE THEIR OWN DECISIONS

Principles, roles, duties and responsibilities when assessing someone’s capacity to make a decision including

- Presumption against incapacity—no preconceived ideas about someone’s abilities. Burden and standard of proof (needs to be first as the overriding principle from which rest of section flow)
- Who can assess capacity?
- When do you need a formal assessment of capacity? Who might make a formal assessment and what does this involve? Give examples
- How does a formal assessment differ from an informal one and when can you rely on an informal assessment? Give examples
- What is meant by a person’s inability to make a decision?—give different examples of how this may arise in everyday life

- Definition of “unwise decisions”—distinction between these and other decisions, for example dangerous ones, and the need to balance the risk to the incapacitated adult or to their property
- Taking all practicable steps to make sure the person understands the decision to be made and to help the person make or communicate a decision—e.g. using easy words, using pictures or photographs, pointing boards or other signalling tools, sign language and interpreters.
- Taking all practicable steps to enhance person’s ability to understand or make a decision for themselves, the obligation to help someone maximise their capacity—e.g the best time and location to assess a particular individual’s capacity, allowing enough time (including allowing them time to discuss with others if they wish) for the process and making the person as comfortable as possible, considering any factors that might affect someone’s capacity such as depression, low self-esteem or fluctuating capacity, or if they are taking medication which may affect their ability to make decisions or process information.
- Role of advocacy in supporting decision making
- What is meant by “reasonable belief” that someone lacks capacity (either here or under the general authority)
- Capacity for particular transactions, e.g making a will or a lasting power of attorney, giving evidence at a trial
- Providing evidence for a court or for legal proceedings or a legal transaction

3. ACTING IN A PERSON’S BEST INTERESTS

Principles, roles, duties and responsibilities when determining someone’s best interests including

- Explain overriding importance of deciding the person’s own best interests—not what others think these might be—and ensuring that decision is not affected by other factors such as convenience to others: give examples
- What to take into account when deciding a person’s best interests—the checklist—explain what each item on checklist in Bill means: give examples, always coming back to the individual concerned:
 - Consider whether the person is likely to have capacity in the future to make the decision, for example if he or she has fluctuating capacity, and whether the decision could be postponed until a later date
 - Ascertain the person’s wishes and feelings—to include, for example, religious or cultural preferences. Include formally or informally expressed views.
 - Take time to allow and encourage the person to participate, or to improve his or her ability to participate, as fully as possible in any action or any decision that will affect him or her. Consult with the person to find out his or her current views, take time to explain what is happening and what decision needs to be made as he or she may have views that could affect the decision or on what is best for them
 - As far as is practicable consult others close to the person, especially close relatives, partners or professional carers. Who should be consulted and when? Who are people “engaged in caring or interested in the welfare of P—does it include advocate? What level or scope of consultation would be required for certain decisions, e.g. serious healthcare decisions. When a range of people is consulted how will consensus be reached?
 - Consider whether the outcome of the action or decision could be achieved in any other way that would be less restrictive of his or her freedom of action—adherence to the principle of minimum intervention.
- Disclosing, making information available to help with ascertaining someone’s best interests—issues of confidentiality

4. GENERAL AUTHORITY TO ACT

Principles, roles, duties and responsibilities when acting under the general authority including

- What is the general authority? How is it defined legally and in practice? Give examples of how it may need to be used.
- What is the scope of the general authority? What sort of acts is it likely to cover? Give examples.
- Who can act under the general authority e.g. carers, health professionals and in what circumstances?
- What is meant by “reasonable”? What would be deemed “unreasonable”? Give examples and illustrations of what would be an unreasonable belief that someone lacks capacity.

- How do you know whether it is “reasonable” for a particular person to do a particular act? Give examples. What if others feel that the person has not acted reasonably?
- Assessing a person’s capacity as part of the general authority. What is meant by a “reasonable belief” that someone lacks capacity?
- When can a person rely on the general authority and when do they need to obtain formal powers? Give examples of when formal powers may be needed.
- Give a definition of a “carer” whether informal or professional
- How will the general authority operate in informal/family situations? Give examples.
- How will the general authority be used by health professionals when making medical treatment decisions? Give examples.
- How will the general authority operate in a social care/welfare situation? Give examples.
- Position of the general authority in the decision making process and “hierarchy”. How the general authority relates to lasting powers of attorney, court-appointed deputies etc.
- Acting in a person lacking capacity’s best interests. How does the concept of best interests specifically relate to the general authority?
- What happens if there is a dispute or concern involving the general authority? Give examples of the kind of dispute or concern which may arise and how this could be resolved.
- Using the money of a person who lacks capacity to pay for expenditure incurred as part of their care.
- Examples of necessary goods and services

5. RESTRICTIONS UPON THE GENERAL AUTHORITY

- Restrictions on what can be done under the general authority. Specifically:
- What would be considered a “substantial risk of significant harm”
- What would be allowed to avert “a substantial risk”
- What would be considered reasonable to prevent a serious deterioration in the person’s condition or to provide “life-sustaining treatment”
- What would happen in an emergency situation, for example if someone required life-saving medical treatment?
- How does this restriction on the general authority relate to how compulsory powers operate under mental health legislation?
- Specific information as to how the general authority operates re healthcare decision-making e.g. consent to serious healthcare decisions
- Liability of person acting under a general authority (e.g. potential penalties under the criminal and civil law for not acting “reasonably”)

6. ATTORNEYS ACTING UNDER A LASTING POWER OF ATTORNEY

Principles, roles, duties and responsibilities when acting under an LPA, including

- How can a Lasting Power of Attorney be made? When should it be made? Who can make it? Does a solicitor need to be involved? How much will it cost?
- Who can be an Attorney? How many attorneys can there be?
- What can a financial/personal welfare attorney do? Give examples
- What restrictions are there on what an attorney can do? Give examples
- What are the powers of the Court in relation to Lasting Powers of Attorney? When does the Court get involved? Give examples
- How can a power be revoked/dissolved? What if a person regains mental capacity?
- What happens in the case of a dispute e.g. between attorneys or with other interested parties
- What can be done about abuse or suspected abuse where a Lasting Power of Attorney exists? What can be done if an Attorney is not doing their job properly?

7. COURT APPOINTED DEPUTIES

Principles, roles, duties and responsibilities when acting as a deputy . including

- Who can be appointed as a deputy?
- How is a deputy appointed? What is the role of the Court?

- How will the Court decide who should be a deputy and what should be the scope of their powers?
- What happens if there is a disagreement over the appointment of a deputy? How is this resolved?
- What does a financial/personal welfare deputy do? Give examples
- What responsibilities does a deputy have towards the incapacitated person? How can deputies be monitored?
- What can be done about unsuitable or ineffective deputies?

8. ROLE OF THE COURT IN DECISION-MAKING

- Nature of the Court—where it sits, who sits in the Court
- How the Court will function—oral hearings and paper applications
- Functions of the Court—what it can and cannot do in respect of adults who lack capacity e.g. make declarations on capacity/incapacity
- Who can make an application to the Court? How do they do this?
- The need for expert evidence
- Rules and Practice Directions
- Where to find more information

9. ADVANCE DECISIONS TO REFUSE TREATMENT

- What is an advance decision to refuse treatment?
- How can an advance decision be made? Does it have to be in writing? Who should be told about it? Where should it be kept? Who will be able to see it? When is it binding?
- What can an advance decision be used for? Give examples
- Effect on decision-making process—how it fits in with other decision-making mechanisms e.g. Lasting Powers of Attorney etc.
- Validity and applicability of an advance decision e.g. who can make one? Factors to take into account in considering validity and applicability. Give examples.
- Liability of person carrying out or continuing treatment where advance decision has been made but not taken into account
- Role of the Court in determining validity and applicability
- Offence of concealing or destroying a written advance decision
- Statements of wishes that do not amount to a statutory advance decision—effect on decision-making process.

10. DECISIONS THAT CANNOT BE TAKEN UNDER THE MENTAL INCAPACITY ACT

- Family relationships etc
- Mental health matters
- Transplants
- Voting rights

11. ABUSE, ILL-TREATMENT AND NEGLECT, GENERAL

- What is abuse? What to look for? Give examples
- “Whistle-blowing”—who to and what about? What do I do if I suspect abuse etc is taking place?
- How will complaints/concerns be dealt with and who will deal with them?
- Role of Social Services/Public Guardian/the Court/the criminal law
- Protection of vulnerable adults—providing and disclosing personal information; confidentiality and the role of the professional

12. ILL-TREATMENT OR WILFUL NEGLECT, CRIMINAL PROCEEDINGS

- Who is this offence aimed at and who is it designed to protect? What do we mean by “having the care of a person”?
- What does “ill-treatment” or “wilful neglect” mean?
- Penalties

13. ROLE AND DUTIES OF THE PUBLIC GUARDIAN

- Who is the Public Guardian and what are his functions?
- How will he discharge his functions in practice e.g. monitoring, investigations, dissemination of information, registering authority: what roles will others have?
- Responsibilities of the Lord Chancellor's Visitors—what is their function?
- How they will operate under the new decision-making framework

14. ROLE AND DUTIES OF THE OFFICIAL SOLICITOR

- What is his function with regard to adults who lack capacity?
- When should he be involved in cases involving such adults? What is his role in the decision-making process and in helping and representing adults who lack capacity? How does he become involved?

15. CHILDREN AND YOUNG PEOPLE UNDER 18

- How the Court will deal with children and young people under 18 who lack capacity

16. RESOLVING DISPUTES

- Ways of resolving disputes
- Healthcare conciliation services
- Social Care conciliation services
- Voluntary sector mediation services
- The role of advocacy in mediation/conciliation
- Role of the Court in resolving disputes
- Legal help and assistance

17. LINKS WITH MENTAL HEALTH LEGISLATION

- What happens when an individual needs to be treated for mental disorder under compulsory powers? How the mental health legislation operates in place of mental incapacity legislation

18. ACCESSING PERSON LACKING CAPACITY'S HEALTH OR OTHER PERSONAL RECORDS (DATA PROTECTION AND CONFIDENTIALITY)**19. RELATIONSHIPS WITH THE LAW OF OTHER COUNTRIES AND JURISDICTIONS (DEPENDENT UPON THE HAGUE CONVENTION PROVISIONS BEING INCLUDED IN LEGISLATION)****20. GLOSSARY****21. CONTACTS AND SOURCES OF FURTHER INFORMATION ON SPECIFIC ISSUES REFERRED TO IN THE CODE**

43. Further memorandum from the Department for Constitutional Affairs (MIB 1222)**IMPLEMENTING THE DRAFT MENTAL INCAPACITY BILL—SUMMARY****INTRODUCTION**

This paper about implementing the draft Mental Incapacity Bill aims to provide the Joint Committee scrutinising the Bill with more information on how the Government would propose to deliver the draft Bill on the ground and the benefits that this would bring.

The summary describes proposed implementation of the Bill as currently drafted and is based on information available in October 2003.

WHY DO WE NEED A BILL?

The current legislative framework for decision making on behalf of those who lack capacity has developed in a piecemeal fashion and does not provide a comprehensive framework. This means that:

- there is a lack of certainty in many instances about whether people are acting within the law

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- too often people are deemed to be incapable of making any decisions, rather than being supported/ enabled to make the decisions for which they do have capacity
 - there are instances where no action is taken, to the detriment of the incapacitated person's well-being, because of uncertainties about the legality of acting
 - it is difficult to identify abuse/ exploitation and to take action against them unless these are clearly criminal in nature
 - people with capacity have no way of taking steps to ensure that their wishes about health and welfare will be taken into account should they lose capacity
 - certain aspects of the common law and case law, particularly the concept of best interests and the validity of advance refusals of treatment, are not widely understood and are open to wide interpretation/misinterpretation
 - there is no clear final arbiter for decisions made on behalf of adults who lack capacity in health and welfare matters

OBJECTIVES OF BILL

The Bill therefore sets out to provide a coherent legislative framework for decision making with or on behalf of mentally incapacitated people, recognising the need to:

- maximise the capacity of those who lack or who may lack capacity to take certain decisions for themselves;
- protect vulnerable adults with mental incapacity issues from abuse and neglect; and,
- provide clarity to families, informal carers and professionals as to when they may act or take decisions on behalf of those incapable of making such decisions themselves.

The Bill's starting point is an assumption of capacity and its underpinning expectation is that everyone should take as many decisions for themselves as they can. The Bill's primary purpose, however, is to explain how to approach decision making in those cases where capacity is in doubt and/or is shown to be lacking.

WHAT ARE THE BENEFITS OF ENACTING THE BILL

The Bill would:

- establish clearly that for the purposes of the decision making process set out in the Bill everyone has the right to be assumed to have capacity unless it is shown (after a prescribed approach) that they do not;
- provide clarity for everyone—mentally incapacitated adults, professionals, family members and lay carers about how to approach decision making where someone may lack or lacks capacity;
- shift the balance in discussions about decision making away from any presumption of incapacity by stipulating a personalised approach based on the individual's capacity to take every individual decision—ie no blanket label of incapacity
- build on the Disability Discrimination Act and the reforms taken forward under Valuing People¹ and No Secrets² in ensuring that people with disabilities are able to access their full civil rights and are protected while doing so. The Bill also complements initiatives such as the National Carers Strategy in providing carers with a legal framework for their approach to people who lack/may lack capacity
- set out a checklist of factors to consider in assessing a person's best interests after a decision has been reached that they lack capacity, giving a clearer role for those who care for that person to be involved in decision making
- by taking account of the principles for decision making set out in the Bill, enable clinicians to treat those unable to give consent when that treatment needs to be given, instead of having to wait until a more serious medical intervention makes this necessary, thereby speeding up the whole clinical process and reducing delay and distress for all concerned.
- contribute to the effective delivery of justice by establishing a dedicated and specialist judicial forum. There would be appropriate mechanisms in place to ensure that people are able to access justice in the most appropriate way possible.
- for those who wish to prepare for a possible future loss of capacity, allow them to determine who would take health and welfare decisions with and for them should they become incapacitated.

¹ Valuing People—A New Strategy for Learning Disabilities for 21st Century—Department of Health White Paper published in March 2001.

² No Secrets—Guidance on developing / implementing multi-agency policies and procedures to protect vulnerable adults from abuse—Department of Health Publication www.doh.gov.uk/scg/nosecrets.htm

- clarify the legal status of advance refusals of treatment by setting out basic requirements as to their validity and applicability

These benefits are undoubtedly important to the daily living of millions of people, though it is impossible to quantify them.

LEGISLATING FOR BEST PRACTICE

The Bill broadly sets out in statute the current common law principles and the current best practice understanding of dealing with mental incapacity. Therefore implementation of the Bill should not require a huge leap in practice in many situations. The Bill should neither require radically new decision making processes to be set up nor an increase in bureaucracy. Rather it will require an embedding of the ethos that the person who lacks capacity is at the heart of the decision making process.

Professional bodies such as the British Medical Association and the Law Society have already produced “best practice” guidance on assessing capacity and aspects of best interests³. The Department of Health has produced guidance and policy statements such as No Secrets, Consent to Medical Treatment⁴ and Valuing People which are all relevant. The DCA has recently produced public information leaflets on best practice within the current laws on mental incapacity⁵.

Implementation of the Bill would build on all of the above. We are already seeking to increase awareness of mental incapacity issues and will continue to do so. In addition we envisage that awareness of the Bill, particularly in the health and social care / welfare fields, would be necessary on implementation.

THE VISION FOR FUTURE SERVICES UNDER THE BILL

The draft Bill would require particular services to be provided to those who lack capacity and the people, either acting professionally or informally, who care for them. Our vision for the services to be provided is that they should be:

- inclusive;
- transparent and accessible;
- proportionate to the resources available;
- non-intrusive, joined up and flexible, and;
- delivered in a way that meets customers’ needs.

ACCESSIBLE SERVICES—INFORMATION AND ADVICE

To provide this service it would be important to provide guidance to those who lack capacity and decision-makers potentially acting on their behalf. We propose to:

- produce a code of practice. This code (or codes) would be developed in close collaboration with key stakeholders and co-ordinated with other Government departments, professional bodies and voluntary agencies who already produce best practice guidance (see attached document)
- expand the current provision of telephone advice and assistance to the public by building upon the expertise of the existing Public Guardianship Office under the new Office of the Public Guardian (OPG)
- produce plain-English literature and websites on mental incapacity including provision of information and assistance in accessible ways, including accessible information specifically targeted at learning disabled people
- work with other Government departments, professional bodies and voluntary agencies on revising or creating guidance available through them on specific, more detailed, mental incapacity issues
- create easy to use, clear and informal court procedures, forms and guidance which would enable customers to access the Office of the Public Guardian and the Court of Protection without the need for legal assistance in the majority of cases
- provide clear explanations and routes to local and informal alternative dispute resolution methods that avoid the need for adversarial, court-based solutions
- continue the role of the Official Solicitor as independent advocate and as advisor on complex, legal matters
- provide specialist but limited publicly funded legal advice where this is necessary for cases of particular seriousness and complexity

³ Assessment of Mental Capacity—Guidance for Doctors and Lawyers www.bma.org.uk/ethics

⁴ Guide to consent for Examination and Treatment 2001—www.doh.gov.uk/consent/guidance.htm

⁵ Making Decisions –Helping people who have difficulty deciding for themselves—www.dca.gov.uk/mental-incapacity

ACCESSIBLE SERVICES—SELF HELP PROCEDURES

Creating a Lasting Power of Attorney (LPA)

Under the Bill adults with capacity would be free to appoint a Financial LPA, a Health & Welfare LPA or both.

Procedures for creating and registering LPAs would closely follow the current procedures for registering Enduring Powers of Attorney (EPAs). The necessary forms and guidance would be available from the OPG. This should enable people to create LPAs without legal assistance. We anticipate two forms, to protect privacy. Guidance would explain factors to consider when choosing an attorney and explain the seriousness of this decision.

The Bill states that it would be necessary to have a “certificate of capacity” when making an LPA. We are still considering whether this is the most appropriate mechanism as it would increase the cost of making an LPA. It may be more advisable for the making of the LPA simply to be witnessed. We need to consider and consult further as to whether we should specify the people who can act as a witness (as in an application for a passport, for instance).

Registration of the LPA would be with the OPG. Either the donor or donee could register depending on whether the power is to be used prior to the donor losing capacity. In either case other persons must be notified who would have the opportunity to challenge the registration. The LPA would only be able to be used once it is registered. Once registered the LPA would be clearly marked as “live”. A register of LPAs would be held by OPG that could then be searched to identify “live” powers.

The Court of Protection would only become involved if the registration of the LPA was contested.

Applying for a single Court order, direction or declaration

Single orders or directions would be required from the Court in order to gain authority for particular decisions. There would be particular requirements for certain financial decisions, as now. Declarations may also be sought from the Court where there is doubt about the scope of someone’s powers under the Bill. This occurs now in the High Court under its inherent jurisdiction. For example, if a doctor wishes to be sure that a particular treatment is in a patient’s best interests.

For simple financial matters the application procedure to the Court would be informal and based on existing processes. Legal representation would not be necessary and applications would be dealt with without a hearing. For declarations or orders on more complex health and welfare matters the procedure is likely to be similar to that used now in the High Court and include the involvement of the Official Solicitor.

Applying for the appointment of a Deputy

For most day to day decisions we envisage that people will be able to act under the general authority.

A Deputy could be appointed under the Bill where a sequence of decisions, rather than a single decision, need to be made on behalf of a person lacking capacity and where an LPA has not been created or is invalid. There could be Financial and/or Health & Welfare Deputies but the Court is likely to prescribe the powers of a Deputy more specifically than these general categories depending on the capacity of the person concerned and the necessity for Deputy powers. Appointments of Deputies are likely to be made for a limited period that can then be reviewed. It would be important for the powers of deputies to be as limited as possible.

The procedure of appointment for Deputies would be similar to that currently used to appoint financial receivers. Those applying to become Deputies would need to demonstrate why an appointment is necessary. Stringent checks on the suitability of the Deputy would be undertaken by the OPG. Interested parties would be given notice of the application and have the opportunity to make representations to the court. If the Court deemed it necessary the Official Solicitor would be required to represent the person concerned. Evidence as to the capacity of the individual concerned would be required either from the parties or arranged by the Court.

For Financial Deputies applications are likely to be dealt with on the papers. For Health & Welfare Deputies it is possible that oral hearings would be more appropriate. Legal representation would not be required in either case. (Save possibly for representation of the incapacitated person by the official solicitor).

A new Court of Protection

The Bill would create a new court, still known as the Court of Protection, that would deal with all decision making for people lacking capacity. The new Court would have responsibility for:

- resolving issues and disputes arising from LPAs, where these cannot be resolved without court intervention
- appointing Deputies to take specified financial and health/welfare decisions

- making single orders or giving directions on both financial and health and welfare matters
- resolving matters where a declaration of lawfulness or capacity is required or where a final arbiter for a dispute is absolutely required. Disputed cases will only go to court where all other dispute resolutions have been exhausted.

The new Court would allow for cases to be determined by judges of differing seniority and specifically nominated officers (from officers of the court to High Court judiciary) depending on the level of seriousness and complexity of the case. Hearings may take place outside of London (using the existing civil court structure and accommodation) with the administration of the Court of Protection undertaken by a centralised administration.

The Court would operate a permission stage for certain types of applications to ensure that litigation is only brought before the Court when it would be of benefit to the person who lacks capacity and to ensure that all parties have exhausted other methods of reaching consensus before going to court. Cases of urgency could, as now, be dealt with via an out of hours service to provide emergency orders.

A new Office of the Public Guardian

There would be a new Office of the Public Guardian (OPG), replacing the existing Public Guardianship Office. Both the new Court and the Office of the Public Guardian would build on the existing court and office structures. The OPG would liaise and work closely with other agencies in financial, health and welfare areas.

As now the OPG would have partly an administrative function and partly a supervisory function. It would be responsible for registering LPAs and for supporting the Court. Its supervisory function would be mainly focused on financial decision making (see below). However, it would have a role in identifying and tackling possible abuse with other agencies by providing a focus for concerns and fielding them to the appropriate agency.

The new Court and OPG would, as now, set fees to cover costs, with a remissions policy where the criteria were met.

Dispute resolution

By setting the person without capacity and those who support and care for them at the heart of the decision making process, the majority of decisions under the Bill should be made by consensus—through the person-centred approach or through informal discussions.

Where consensus is not possible we have considered how best to tackle this. Research into family disputes tackled by the courts shows that solutions to very personal family difficulties are least likely to be resolved successfully if determined by a court. We do not therefore wish to suggest that people see the Court of Protection as the proper place for resolving all difficulties and disputes when there are mechanisms that are better suited than the Court. Therefore we are exploring other processes to resolve difficulties in decision making.

Financial decisions

As financial disputes tend to be more fact-based these would continue be resolved through mechanisms tried and tested in the Court of Protection and Public Guardianship Office.

Health and social care decisions

We propose to link into existing formal and informal systems in the NHS for resolving many of the disagreements about healthcare, such as the Patient Advice and Liaison Service (PALS) and Independent Complaints Advisory Services (ICAS). Subject to current legislation, from April 2004 the Commission for Healthcare Audit and Inspection (CHAI) will have total responsibility for the independent stage of the complaints procedure. If a complainant remains unhappy after the NHS complaints procedure has been exhausted then they can complain to the Health Service Ombudsman.

We are also consulting on proposals to reform the way clinical negligence cases are handled in the NHS and proposals for bringing the complaints and clinical negligence systems together. Whatever systems are put in place in the future we are working to ensure that these will be accessible by incapacitated patients when they interface with the NHS.

In social services difficulties tend to be resolved through discussions to negotiate the care package until it is more acceptable to all parties. There is a formal complaints and independent review procedure, again ending with an Ombudsman. Subject to legislation, from 2004 the new Commission for Social Care Inspection (CSCI) will conduct the independent review stage of the procedure, where a complaint is not resolved at local authority level.

Where there is joint provision, or other forms of overlap between health and social care, DH are exploring where a joint approach is necessary to ensure a robust and reliable complaints procedure, including for people who lack capacity.

Disputes on other welfare decisions

We are in discussion with ODPM and DWP to explore the mechanisms available to review disputes in other welfare decisions—e.g. housing, benefits appointees.

PROTECTION AND SUPERVISION

As now, it is important that we ensure that those who have authority to act on behalf of adults who lack capacity do not abuse their power.

Councils with social services responsibilities (CSSRs) have developed non statutory multi-agency Adult Protection Committees (APCs) as part of the Government's "No Secrets" policy. APCs set the general policy on protecting vulnerable adults from abuse in the context of "No Secrets". APCs ensure that multi-agency Codes of Practice are in place and working well. With regard to individual cases of abuse, these are investigated under APC guidelines by individual designated officers from health and social care involving the police, as appropriate. APCs appear to be well-placed to set up and over see the processes needed to deal with cases arising out of the Bill where neglect or ill-treatment are alleged.

THE OFFICE OF THE PUBLIC GUARDIAN

Under the Bill, the Public Guardian has a supervisory role in monitoring LPAs and Deputies. The OPG's supervisory role would be geared to risk and would intrude as little as possible. The focus would be on supervision of Deputies. Deputies would have a new and unique relationship with the person lacking capacity under the Bill and further work is being undertaken to understand how this will affect the monitoring requirements.

Where there are allegations of possible abuse (of any kind) Office of the Public Guardian would liaise closely with all of the agencies and individuals involved, including social services, the police, voluntary organisations and Adult Protection Committees. The existing Public Guardianship Office is already establishing and developing partnerships with local authorities and other bodies to ensure that any concerns about a person lacking capacity are highlighted and acted upon. Work is also in progress to establish an investigation unit.

The OPG is supported by the currently named Lord Chancellor's Visitors. Visitors would be able to visit attorneys and Deputies if so directed and provide an independent and impartial report on circumstances to the Court.

Health and social care review bodies

From December 2003, Patient and Public Involvement Forums (PPIFs) will monitor the effectiveness of PALS and will, in 2004–05 become responsible for the provision or commissioning of ICAS. Nationally, PPIFs and ICAS' work will be monitored and co-ordinated by The Commission for Patient and Public Involvement in Health who will report to the Secretary of State. Local Authority Overview and Scrutiny Committees (OSCs) are scrutinising and reviewing health services both in range and standards.

Subject to Parliamentary approval, CHAI will from April 2004 carry out reviews and investigations into NHS services at both local and national levels (this role is currently carried out by the Commission for Health Improvement). It will also be responsible for the regulation of independent health care.

CSCI will be responsible for monitoring standards of care in residential homes. Part of that remit may well include the accessibility to dispute mechanisms, quality of decision-making and recording etc. The Inspectorate could equally act upon specific concerns to quality assure the service provided in any particular home or group of homes.

Other Review bodies

We are working with ODPM to explore the mechanisms available to review disputes in other welfare decisions—e.g. housing, planning.

CURRENT COSTS OF SERVICE RELATING TO MENTAL INCAPACITY

Unfortunately, we are unable to calculate the current costs handling mental incapacity because there is no formal means of recording many of the issues that arise.

The current running costs of the existing PGO and Court of Protection are £24.6m with £10m collected in fees. These relate to financial decision-making only.

The Official Solicitor has a public subsidy of about £6m overall at present which also covers his Public Trust functions, with approximately £528k directly attributable to the type of cases that would arise under the new jurisdiction. This does not take into account the information and advice provided by both lawyers and caseworkers, which prevent cases coming to court or provide a forum for settlement by discussion and negotiation.

Outside of the Official Solicitor there are no clear costs for the serious health and welfare disputes which come before the High Court because they are swept up within larger costs.

We are also unable to say exactly how much at present is spent on provision of legal advice and assistance because mental incapacity is not a category of law currently recorded. The same situation arises in the NHS and social care where there is also no current baseline.

COSTS ARISING FROM IMPLEMENTATION OF THE BILL

It follows that all the costs we have estimated below assume a zero baseline of activity apart from figures for the Public Guardian and the Official Solicitor. We have not anticipated that there would be significant costs arising from implementation because the Bill largely builds upon the current common law and best practice.

Costs identified to date would fall in the following areas:

Set-up costs

- public advice and information—there would be costs in producing a code of practice and revising accompanying literature, information and guidance to be made available to the public including providing information and advice in ways that ensure the widest possible access to all areas of society
- process changes and expansion at the Court of Protection and PGO—the new Court and OPG would require new systems and would take on new workload
- awareness and guidance—it is anticipated that health and social care professionals in particular would need a clearer understanding of the requirements of the Bill
- Some costs to voluntary and small business sector—awareness raising and reviewing practice and evidence.

On-going running costs

- running costs at the Court of Protection and OPG—these costs should be largely met through fee income
- on-going information costs—in particular the telephone advice at the OPG and keeping guidance up-to-date and accessible
- costs for the Official Solicitor—there may be a small increase on the current demand
- legal aid costs—would be restricted to serious, legal matters so should not increase significantly above current levels
- costs of dispute resolution in health and social care—should be mainly absorbed within existing mechanisms, with possible small increases to cover mental incapacity issues
- costs of health and social care staff—staff who are currently not adopting best practice would need to deal with people who may lack capacity in accordance with the requirements of the Bill, if they do not do so now, which could increase costs—this is difficult to assess
- there may be additional, minimal on-going costs to the small business sector and other local authority costs. These have still to be fully assessed.

Summary of costs

Preliminary estimates indicate set up costs may be in the region of around £17m and on-going annual costs of a further £18.5m. These are very much initial estimates. Significant refinements are likely before the Bill is introduced in to Parliament. In particular further work will be undertaken to estimate current expenditure. It is likely that final cost estimates will be lower after the expenditure at present has been taken into account.

Additionally, it has always been envisaged that the consultation and pre-legislative scrutiny will help identify policy developments for the final Bill, which may also impact upon costs. Figures at this stage should therefore be seen only as a rough indication of the likely scale of the cost of the Bill. It is government policy that no Bill is brought before Parliament without its cost implications being fully considered and appropriate funding having been identified.

October 2003

Witnesses: **The Lord Filkin, CBE**, a Member of the House of Lords, Parliamentary Under-Secretary of State, Department for Constitutional Affairs; **Ms Claire Johnston**, Head of Legal Advice and Legislation Division; **Ms Rosie Winterton**, a Member of the House of Commons, Minister of State, Department of Health; and **Mr Adrian Sieff**, Head of Mental Health Legislation, examined.

Q704 Chairman: Perhaps I could start by saying good afternoon and thank you very much for coming in. We are grateful for the letter we had of 16 October and the departmental papers that were attached to it. The session, as you know, is open to the public and is being recorded for broadcasting on the Parliament channel at 6 o'clock on Sunday evening. There will be a verbatim transcript, which you will be asked to check. The proceedings will have to be adjourned if there are divisions in either House. If you wish to follow up any points which either we do not reach or you wish to expand on any points made in the session, you can write to us after the meeting, but we need to receive those comments within a week of today. We remind all our witnesses that we are here not to write a White Paper on Mental Incapacity but to report on a Draft Bill, and therefore all the questions are structured around the Bill. Would you like to introduce yourselves and your officials, and, if you wish, to make an opening statement.

Lord Filkin: I am Geoff Filkin, Minister at the Department for Constitutional Affairs, taking the Bill forward, with my colleague, Rosie Winterton. The DCA has the specific formal lead, and of course in fact took over much of the excellent work Rosie Winterton did when she was a Minister in the Lord Chancellor's Department.

Ms Winterton: Rosie Winterton, Minister of State at the Department of Health, obviously working closely with DCA on the Bill. I am delighted that it is before us, as you can imagine given the input I had in a previous existence.

Mr Sieff: I am Adrian Sieff, and I am the Head of Mental Health Legislation in the Department of Health.

Ms Johnston: My name is Claire Johnston. I am Head of the legal team at DCA working on the Draft Mental Incapacity Bill.

Q705 Chairman: Do you wish to make an opening statement?

Lord Filkin: Perhaps briefly, just to position the Bill in terms of the DCA's wider programme. I also have one or two comments on the draft nature of the Bill and the scrutiny process. The Bill fits very strongly

within the vision for the Department for Constitutional Affairs of trying to ensure that people, especially those who are particularly vulnerable, have their rights protected in society. It would be hard to find individuals who have a greater need for effective protection than the people we are talking about in this respect.

The Committee suspended for a division.

Lord Filkin: The process of the Draft Bill I think allows the involvement of wider interest groups in society in important and difficult areas at a time when the Government is not completely locked on to detail. It therefore allows a process of testing the issues and the ideas in ways that probably increase the potential influence of wider society, and it is better that it is done then rather than during the passage of the Bill itself, when inevitably governments tend to become rather entrenched in their views. Therefore, I think that process is in principle healthy. What I have heard is that the way the Committee has been facilitating that engagement has really come to life and allowed very vigorous engagement of many people outside who would wish to put their views on this area. We are really pleased that the pre-legislative scrutiny process through this Committee is so much coming alive.

Q706 Chairman: What are the Department's plans for introducing the Mental Incapacity Bill as a result of what you are hearing? Do you think there will be much more preparation and consultation required before a Bill can be presented to Parliament? We had been working to a very tight timetable on the expectation that the Bill would be introduced early in the new session.

Lord Filkin: There are a number of areas which I am sure we will touch on later. The lines of inquiry and the probing and the evidence have helped us to develop our thinking. We have not been static on this. We have, in a sense, started to reflect on areas where there is a need for either greater clarification or deepening how we would actually implement it. Above all—and I think our joint presence illustrates that—it is very important that the Department for Constitutional Affairs and the Department of

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Health work on the Bill as joint chaplains, which is our stance, both in terms of getting the law right but also thinking through how it would be applied in practice. I cannot say when or if there will be legislation, but there is certainly a vigorous will within both departments to try to move forward on some very important and complex issues.

Q707 Chairman: There has been extensive consultation over the years on this subject. Are you forming the view that following on the publication of the report you will need even further consultation with interested parties before you can begin the move of introducing the Bill?

Lord Filkin: In my experience, you never totally stop consulting. I do not think after this there will be a White Paper, but clearly, in the light of this, we took a view on something that needed further development. If I can give you a clear instance, there has been some vigorous debate about the general authority. The way government works well in my experience is that you try to at least engage people who are interested in that before you finally commit yourself to the ultimate detail of the Bill, and that would be the stance I would want officials to take on it, as an interactive process.

Q708 Chairman: A question for the Minister of State: we know the Department of Health is considering a Draft Mental Health Bill. If it were the fact that this Bill, when it comes to Parliament, was implemented before you were able to introduce a Mental Health Bill, would the provisions in the Bill link with the present 1983 Mental Health Act? If they were running alongside each other, would you foresee any problems? Should we be taking that into account in our thinking about this Bill?

Ms Winterton: First of all, with the Draft Mental Health Bill that we published last summer, we received something like 2,000 responses to the consultation. We are working with stakeholders still to refine it and make sure that we are taking account of some of the responses that we have received to that. However, we are obviously committed to reforming mental health legislation and we will publish a Bill as soon as finance and parliamentary time allows. In the mean time, we are working very closely with colleagues in the DCA to make sure that not only is the 1983 Act compatible with the Mental Incapacity Bill but also that the future Mental Health Bill is as well. Of course, they do address two quite separate issues, one dealing with people who have lost the capacity to consent to treatment and the other dealing with people who do not wish to consent to treatment but for whom treatment is felt to be a necessity.

Q709 Chairman: What about the Bournemouth Gap, as described?

Ms Winterton: That is obviously something where we believe that the law as it currently stands is sufficient, but we do want to look at whether we could take the opportunity of new legislation to provide people who were in that kind of long-term situation without capacity to be able to have access

to some of the same rights—advocacy, nominated person, mental health review tribunal. There is an issue about where that would most satisfactorily lie, whether it would be within the Mental Incapacity Bill or the Mental Health Bill.

Q710 Mrs Browning: We are waiting to see what the European Court has to say on Bournemouth. You seem to indicate that you feel the Bournemouth case was the case of a person who should have been detained, although it was a voluntary detention, but in fact, the case there was something which went quite against the spirit of this Bill, which is hopefully to empower carers and people close to that person to advocate for them. We have heard a lot about independent advocacy, and no doubt we will come on to that, but surely the point about the Bournemouth case was that the carers who knew that person best were rejected by the so-called professionals all the way along the line, and that is what caused the case ultimately to come to court. How do you see this particular Bill rectifying that particular situation? It has been said to us that this is a charter for parents and carers. Where do parents and carers come into the Mental Incapacity Bill, particularly in respect of those carers in the Bournemouth case?

Ms Winterton: If there were a situation like that, one of the things I would expect the Court of Protection to do at quite an early stage would be to decide whether, for example, a deputy might be appointed, because obviously in that case there was not a lasting power of attorney with somebody else, and in terms of the basic principles of the Bill that the person who would perhaps be appointed as a deputy would have a stronger ability to intervene in the care plan as well. Within that, I think the Bill also says that the patient's best interests should always be taken into account, and carers in that situation would have a far greater input than perhaps the situation is at the moment, where there is not so much clarity about how the views of carers should be taken into account.

Q711 Mrs Browning: I am sorry to press you on this, but of course, it was under mental health legislation that the young man in the Bournemouth was taken in. I am not clear in my mind which would take precedence, the mental health legislation or this particular legislation.

Ms Winterton: I think in the particular case, initially the person was considered to be compliant, but there was no longer-term ability to challenge that, and after the situation with the carers I think there was a detention, as you say, under the Mental Health Act, but I think it was after he had come back into hospital that the Mental Health Act was used. I am not quite clear about the actual sequence of events; that is as I understand it, that the person returned to hospital, and after that, because there were various issues legally, the Mental Health Act was invoked. I do not know whether Claire might add anything to that in terms of the details of when the Mental Health Act was instituted in that case.

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Ms Johnston: I think it might be more appropriate for Adrian to help.

Mr Sieff: What we are talking about is a person who was in hospital under informal care, but because they were incapacitated and compliant, the Mental Health Act was not used. The carers then wanted the person to be taken home, they felt it was more appropriate for that person to be at home, and it was only after this stage that the person was sectioned. If I remember correctly, the court case is about the period of time before the person was under section, when they were in informal care and whether, because they were compliant, the Mental Health Act should have been applied and therefore their rights had been abused.

Q712 Mrs Browning: I am sorry to pursue this, but I think it is quite important because the Bournemouth case is the case which I think many of us have in mind in terms of whether this particular legislation is going to prevent something like that happening again because it would empower carers to be listened to at an early stage. The carers in the Bournemouth case had commissioned me to raise this in a previous debate, which I initiated in the House a few weeks ago, but in their own words, if this could perhaps put it into context, as carers, as the advocates closest to the person who was taken in under the auspices of the mental health legislation, they were rejected by the professionals in that psychiatric hospital, and ultimately, they told me, it was even suggested that they themselves needed psychiatric treatment because they tried to be robust advocates on behalf of an autistic young man who should never have been taken in there in the first place. What I am asking you is, are you absolutely certain—this was part of the Chairman's question—that what you are putting before us in this legislation is going to deal with cases like that? Are the people who really are acting in the best interests of somebody, and who very often find themselves up against so-called professionals who do not have the full picture, going to be empowered by the legislation you are putting in front of us?

Ms Winterton: That is what I was saying. Whilst we believe that we are right in the current situation with regard to this particular case, what we do want to do in the future is to give the patient in that scenario the same access, for example, to advocacy and a nominated person and access to a tribunal if after a 28-day period they continued to be kept in those circumstances, and in those circumstances, I would expect that the carers would be the nominated persons.

Q713 Baroness McIntosh of Hudnall: Can I press you a little on this question of precedence as between the two Bills, whether it be the existing Mental Health Act or one envisaged to be on the statute books in the future? One might imagine a situation in which somebody is sectioned under the Mental Health Act, for whatever reason. As a result of whatever it is that causes that person to be sectioned, he or she might be incapacitated, within the terms specified by the Draft Bill that we are looking at

now. In those circumstances, what I would like to know is whether that person's rights under the Bill we are now examining would take precedence over the rights of those who had caused that person to be sectioned, to submit that person to treatment, or indeed to take decisions for him or her. It is a question of practical reality at the moment at which the provisions of both Bills might be in operation in one case.

Ms Winterton: Under the Mental Health Bill and under the Mental Health Act the necessity for treatment, because the person is either a risk to themselves or to other people, would apply whether the person did or did not have capacity, so in that sense, because we are looking at compulsory treatment with detention, that would override the ability—I do not know whether you are meaning would the person who perhaps had lasting power of attorney have the right to dictate treatment. Is that the kind of thing that you are getting at?

Q714 Baroness McIntosh of Hudnall: For example; not exclusively.

Ms Winterton: What I would say there is that I think we do need to look in terms of things like codes of practice from the Mental Health Bill as to how one clinician would consult with somebody who had lasting power of attorney, would look of issues of advance directives. You could not say that they would override a clinician's decision in those circumstances, but I certainly think that, in terms of some of the principles of the Bill, even in cases of compulsory treatment, there should be as much effort made as possible to try to consult with the patient. So I would expect that that would happen, and that those wishes would be taken into account, but because we are talking about a high-crisis situation, the necessity does overtake the consent.

Lord Filkin: As we would understand it, the Mental Health Act would take precedence in relation to treatment for mental disorder, and the Mental Incapacity Act would apply to all other situations.

Q715 Baroness Knight of Collingtree: You were kind enough, Lord Filkin, to send us last week a letter giving the reasons why the Bill was being introduced, and from that we understand that you are satisfied that the Bill is necessary. However, we have already received very large numbers of letters expressing concern, although some have expressed support for the Bill, and some witnesses have, but there is a really sharp division of opinion about this, and I want to ask you whether you think the Bill is going to improve significantly on the present situation. I am particularly thinking about an article in a national newspaper only a few days ago following up a case two weeks ago of a 91-year old woman in hospital whose food and liquid was stopped and was only re-started when her grandson got a legal judgment to do so. The article to which I refer says this legislation would allow the routine neglect and dehydration to death of mentally incapacitated patients on the orders of a variety of different agents, many of whom may have nothing to do with either medicine or the patient's family. The

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writer goes on to describe this as sinister, and she thinks court-appointed deputies, attorneys and even people who simply claim, with no validity, to know the wishes of the patient will be empowered to authorise non-treatment, including the withdrawal of food and liquids. That was not written by somebody of no importance or with no knowledge of law; it was written by the senior lecturer in the Department of Law at the London Metropolitan University. That statement worries me, and I would like to set it beside the question I have asked you. Thinking of what is said here, do you really feel that the Bill is going to improve the present situation as you hope?

Lord Filkin: Maybe I could make a general comment first and then use the interesting example you gave and respond to that specifically. On the generality, the reason we are confident that the Bill will make a significant improvement is that, first of all, it is addressing issues that affect a very large number of people and in many cases matter a lot to them. It does not mean to say we will automatically succeed in that aim, but it is an issue that is going to be of increasing importance to all of us in the coming years. So it potentially has a very widespread impact and relevance. Why, specifically, we are confident it will improve the situation is because it establishes very clear statutory principles as to how people are to be treated and cared for in a context where we believe, and many of the people who gave evidence to you affirm, that very many people are being treated as incapable when in fact they are not. It is far too easy to make a one-off decision for all people for all time under all circumstances, to label them incapable and then to deprive them of what we think are important rights of involvement and decision-making. We are confident that the Bill will push back that bad practice through the principles it enshrines, the first and perhaps the most important being that everybody has to start by assuming that this person is capable. Whatever label they have had put on them in the past is by the bye; you have to look at the evidence that this person is incapable at the specific point in time that there is an issue. That seems to us to be fundamental, the presumption of capacity. You have then to move on from that in practice. The second is the functional approach to capacity, which says essentially: does this person have capacity for the specific issue that we are about? In other words, is it possible for them to make that decision or, put another way, do we need to take this decision at this point in time or could we defer the decision until the person has capacity and is capable of taking that decision? So we are enshrining in statute very clear principles as to how both professionals and individuals are meant to address the care of people, and we think it goes a very long way to ensuring that their best interest, which is clearly one of the themes running throughout the Bill, will in practice be met in many more situations than is currently the case. We are confident, reassured in part by the experience in Scotland, that this will make significant progress. Turning to your specific illustration—and I read the *Daily Mail* article that you referred to—we think the Bill would improve the situation for that lady,

because under the Bill her family would have to be consulted about her care, and that seems to us to have been what went fundamentally wrong in that situation. The family would have a right to be consulted, and the doctors would know that they would have to act in her best interests. Thirdly, if the doctors, despite that consultation, were still of the view that it was appropriate and they were charging ahead in ways that the BMA and others see as a fundamentally bad medical practice, in that extreme situation, that family would have easier access to court than they have now to challenge them, because it will be easier to go to the new Court of Protection than it is to go to the High Court. The Bill would not allow routine neglect and dehydration. It is for those reasons, in generality, that we are confident that the Bill will strengthen protection, and we are confident in the specific dreadful example you instance that that would have been significantly less likely to have happened if this legislation had been in place.

Q716 Baroness Knight of Collingtree: Would you then say that the Bill itself, as it stands, as we are considering it here, actually will end the practice, about which there is now a very considerable body of evidence that, whatever the relatives say, the doctors will, having classed giving food and liquid as medical treatment, order that treatment to cease?

Lord Filkin: It is very dangerous, as a politician, to say “never”, as you know better than I. I think in fact it was already clear in the BMA guidance that the doctors should not have acted in the way they did under current law. When this Bill is in place, as we hope, we believe it will significantly reduce the likelihood of what you describe happening, because there would be consultation with the families. The best interests of the patient would be a clear statutory factor that had to be considered, and if the family, for example, in that situation said, “It has always been clear that she would never have wanted this sort of treatment, and our judgment about her is that she would never want this to happen,” the doctors would be committing an offence if they acted in defiance of that, if they proceeded in the light of clear evidence that that was not what she wanted.

Q717 Baroness Knight of Collingtree: That is a case where of course one would perfectly well agree that where a patient says “Please don’t give me food through a tube” then that patient’s wishes should be accepted. I am not speaking so much of that as the patients who have never asked to be denied food and liquid but in fact are, and their relatives are too nervous to argue, believing that the hospital always knows best, until it is almost too late. There are now many instances of that on record. I am grateful for what you have said and I hope very much it will be the case.

Lord Filkin: Care practices take a while to implement. Nobody claims that by passing a law you suddenly change all the practice, but it will be very clear indeed in principle, which is why there is guidance to professions and from professions to their practitioners, that in the situation you describe, which is in essence one of the most difficult and

painful decisions that have to be made, as to whether to sustain a medical treatment by artificial nutrition and hydration when there is no longer a medical reason for it, the doctors in that situation would be expected to consult with the relatives and ask, "Is there anything you know about her situation that would help us make this decision?" The second issue would be, in very difficult situations like this, the Bill will provide easier access to go to court, so that a doctor in that situation would be well advised to be cautious, with no immediate need to act, and to go to the Court of Protection and seek the Court's guidance on that, which of course would also allow the relatives, if they had not already been listened to, the opportunity to express their views very clearly to the Court.

Q718 Chairman: You have mentioned guidance, and we will have some questions later on the Code of Practice, but would you expect the Code of Practice to be published in draft at the same time as the Bill was introduced in Parliament?

Lord Filkin: It would certainly be our aim. It will partly depend on how much work we think we need to do to the codes of practice in the light of the consideration of the views of the Committee, and how early we get a legislative slot if we are successful. It would clearly be our aim because, in my experience, it makes for a better informed Committee process in both Houses if you have principles and codes, particularly when under this Bill the codes of practice will rightly have to carry quite a lot of the burden of expressing the principles.

Q719 Huw Irranca-Davies: In your opening statement you warmly welcomed the wide consultation and the work of the Joint Committee in bringing forward quite a multiplicity of views with respect to this Bill. One of the things we have heard widely divergent views on is the issue of human rights and whether human rights are enshrined within this Bill. If I were to simply ask you "Do you feel that, as currently drafted, this is compliant with human rights legislation?" I am sure the response would be "Yes." If I turn it on its head, can I ask what would your response be to those—and in particular I can refer to witnesses we saw yesterday in this Committee—who have referred to this Bill as knocking back 20 years the rights of those who have learning disabilities and those who are particularly concerned about advocacy? How would you respond to their criticisms of this Bill?

Lord Filkin: Let me make some general responses and then some legal responses. I have not yet read what was said, so I should be cautious in what I am saying until I have considered it in detail, although I have heard about the power of their arguments and how well they put it across. The specific reason is that at heart the Bill has an ethic running through it, the ethic being that the individual whom we are in this specific instance considering and what is in their best interests is the fundamental principle that the Bill is all about. In a sense, it is trying to put legislation and processes around saying that the only basis for taking decisions about a person who may

have lost capacity is if you are doing it in their very best interests, not for the convenience of relatives or hospitals or anyone else. In essence, that is about confirming a fundamental right. More specifically and technically, obviously we have considered it, and our judgment is strongly that it is compliant. That view is shared by the Joint Committee on Human Rights, who saw no significant risk of incompatibility. The new Court of Protection, taking the example we just spoke about, provides a better route for testing particularly Article 6 rights than currently; it is easier to go to the Court of Protection than it is to go to the High Court.

Q720 Huw Irranca-Davies: Colleagues later will want to go into issues of general authority, so I will not touch directly on that, but you said in your opening statement that those who are particularly vulnerable have their rights protected and that is the essence of this Bill, but are you confident, in light of what we have heard from some of our witnesses, that the balance is correct in terms of their individual interests as opposed to the interests of the wider community, which may have a different view of what would be the best approach?

Lord Filkin: If I have understood you correctly, many of those concerns hinged around the general authority. It is either that we have failed to communicate clearly—in other words there has been misunderstanding—or there is an area of real concern, and I am not going to jump in and say it is neither of those at this stage. In essence, the short answer is no, I think we want to give some very serious thought to some of those anxieties, because obviously we are most concerned that the Bill is felt to be of benefit as well as being actually a benefit. So we have to look at those issues. In other words, our minds are not closed; we are not thinking we have got it perfect. I would not want that by thinking there was necessarily an easy escape route; in other words, just knocking off the general authority is not necessarily a wonderful answer, because what the general authority does is try to put in place a legal authority, albeit circumscribed by certain tests, which does not mean that people have to constantly feel that they are in a legal fog or that they have to constantly go back to court. There is some evidence from Scotland that because there is not a general authority, for example, in the Scottish Act, people are probably going to lawyers, going to court, more than is desirable or necessary. Whether there is a way between that Scylla and Charybdis I am not certain but that is, I think, the tension we want to address.

Q721 Huw Irranca-Davies: You have also alluded in your opening statement to the fact that your thinking is, as you have just reflected, open to change and modification based on what we have heard. Are there any other areas, in terms of the protection of the human rights of an individual, where you think some development might be seen in your thinking?

Lord Filkin: I cannot think of anything specifically in terms of the legislation. As ever, how you implement the legislation is an even bigger challenge than getting the legislation right. We are going to

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have a lot of thinking, as we are actively doing, across government, and particularly the Department of Health, about how it is implemented, because you can get a situation where the law is fine but the practice is not.

Q722 Baroness Fookes: You will be aware that we had as early witnesses representatives of Scotland, who clearly thought that their brand of legislation was superior to this Draft Bill. Could I ask you first if there are any other lessons than the one you referred to about the general authority that we could learn from the Scottish experience?

Lord Filkin: We have been enormously helped by having their Bill a law and implemented, and we have sought to have a very close learning relationship with our Scottish colleagues, without necessarily taking the view that all we need to do is to copy their Act. I do not think that is the case. I will probably touch on one or two. There is the real importance of getting codes of practice right, and we touched on that earlier, and their experience reinforces that. I have already touched on the problem about not over-burdening it with a formal assessment of capacity. (General practitioners in Scotland threatened to go on strike because they were filling in pieces of paper rather than giving care.) We are concerned about the lack of clarity in their Bill, as I instanced, on informal powers, what led people to seek informal powers more than is desirable. That is the main issue. But this process has not stopped, and I think we would be wise to keep the dialogue running.

Q723 Baroness Fookes: Specifically, they lay great stress on their statement of principles, which is not in our draft legislation precisely in that format. Can you tell us why you have decided on the best interest as opposed to a statement of principles or something being of benefit?

Lord Filkin: The best interest is one of the principles—probably it is a fundamental principle. It is really saying that people are making decisions in a situation where there is not capacity and they are not at liberty to act at large; they can only act in terms of the best interest. Secondly, there are a number of other principles in our Bill: the presumption of capacity, the functional test of capacity—it sounds a dreadful expression; in other words, making a judgment about capacity at the specific point in time when you need to rather than speaking once and for all. There is a requirement to take all practical steps to help people make decisions, in other words, not just making it a black and white issue. Also, when it is clear that a person does not have capacity, still striving to take their wishes into account. These are some of the principles that are in the Bill, and we think those are right principles. We are certainly open to reflection as to whether it would give people more comfort to put some of those principles all together in one section. We are not saying that we will do that, but we need to think about why we should not have a section

making it very clear rather than requiring the effort of going through the whole Bill to find the principles at various points in it.

Q724 Baroness Fookes: Some witnesses thought it would have been better if the statement that capacity is to be assumed unless proved otherwise should be at the very forefront of the Bill, Clause 1.

Lord Filkin: I think I have covered that in what I said previously. If we do decide to re-order, that would be a powerful opening statement. The whole Bill hangs on that, does it not? I am personally sympathetic, but that was not meant to be seen as a governmental commitment.

Q725 Chairman: Certainly, from the evidence we have heard, the perception of the Bill might be improved if the statement of principle were actually in the Bill rather than being hidden away in the various clauses. A number of witnesses would feel more comfortable and therefore the perception would be improved.

Lord Filkin: I hear that, and although one always takes parliamentary counsel very seriously, if the public would feel more confident about something, we would take that even more seriously.

Q726 Mrs Humble: Can I just ask you about the practical implementation of the legislation? When this Draft Bill in near enough this form, assuming that, becomes law, how would the two pieces of legislation be implemented, the Scottish Act and a new Act in England and Wales? Would it be based on the domicile of the individual concerned or would it be based upon the location of that individual should a decision have to be made about them? For example, somebody living in England, making an advance directive to refuse treatment, appointing somebody with lasting power of attorney, with a degenerative disease that will ultimately be terminal, decides in their last months to visit Scotland on holiday and, God forbid, they have an acute episode when they are there and find themselves in Edinburgh Royal Infirmary. They are incapable of making any decision. Would the advance directive to refuse treatment under the terms of the English legislation, which would apply to them if they were still at home in London or Blackpool, apply in Scotland or not?

Lord Filkin: It is such a good question that I should take legal advice on it.

Ms Johnston: This is a question about private international law, which is one of the most obscure aspects of the law that there is. Schedule 3 of the Scottish Act does deal with that. It deals with the jurisdiction of the Scottish courts. Before introduction we will have to add a bit to our Bill which deals with matching provisions. There are similar problems in relation to the Children Act, so it is an issue that has to be dealt with, but it is one of the areas where the Draft Bill does not cover the ground and will have to. Just for your information, the Scottish Act provides that the Scottish judicial and administrative authority can deal with matters if the adult is habitually resident, which is usually the

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test in international law, but there are complications in relation to real property, so land, the principle tending to be that the law of the country where land is situated has to apply to disputes about that land. I do not want to go on too much further. It is definitely a matter that would have to be dealt with before introduction.

Q727 Mrs Humble: So you are saying to me—and I am not a lawyer; this is not a trick question—that you cannot answer what would happen in my hypothetical case, but you will at some point be looking at it. I just wonder if you might be able to give us some advice before we conclude our deliberations.

Ms Johnston: The general principle would be that the law of the country in which you are habitually resident should apply. There are lots of cases on what that means.

Lord Filkin: As a non-lawyer, that feels right. If we can give further detail than that within two weeks, we will do so.

Q728 Mrs Browning: Could I ask you about the definition of “capacity” in the Draft Bill? Do you think the requirement for evidence of impairment of mental functioning and of impaired decision-making capacity before action is taken in a person’s best interests is likely to be workable? Who is actually going to be responsible for this? Under what circumstances will a second opinion be required?

Lord Filkin: In many cases, it would be known that the person had had a learning disability, say, from birth, or had had a very serious illness which had deprived them of significant capacity. So in some situations there would be evidence that clearly pointed to that. The second question is who would have to decide. The answer would be anybody who was in a position whereby they might have to make a decision in the place of the person themselves, so it could be anyone from a relative deciding whether to take them on holiday or not to and a doctor deciding whether or not medical treatment was needed. Again, the diversity of the situations is relevant to the judgment, because if the judgment about incapacity was uncertain, and the consequence of the action was significant, for example, a major operation, then in that situation you would expect that the decision-maker, because there was uncertainty about capacity, would seek a second opinion and/or guidance from the Court of Protection. That is why we have both those measures and principles in the Bill. As you know, we are dealing with an enormous variety of circumstances when a decision may have to be taken on behalf of someone else. Those are the broad principles that would apply.

Q729 Mrs Browning: Can I just ask you about that, because you seem to be indicating that a long-standing diagnosis or accepted condition should in perpetuity be recognised by professionals and non-professionals as a lack of capacity, and yet we heard yesterday from adults with learning disabilities about their concerns about this particular Bill,

particularly, for example, in some cases—but only in some cases—where parents and carers took decisions about them, the diagnosis and the lifelong condition is not being questioned. What they are questioning is people’s ability to recognise that in fact, in many circumstances, they do have capacity, and in particular, very worrying evidence from directors of social services about the amount of abuse that goes on, particularly of elderly and learning disabled adults. What I am concerned about, Lord Filkin, in your answer to us is that it seems to be contrary to the very ethos of this legislation, which assumes capacity and then has to be proven not to be, therefore what went before surely has to be tested again against the benchmarks of this Bill. If I could add to that, what about those very difficult cases where capacity necessarily fluctuates, psychiatric conditions where people do have capacity and then it fluctuates with current mental illness? You cannot just assume that, because there is a diagnosis, there is no capacity.

Lord Filkin: No, I agree with that. The impairment is an initial hurdle as part of an assessment of capacity which needs to consider other issues as well. In some situations, the ones I gave, one would have to look at whether the lack of capacity was clear or not. That would be a further question, and I instanced that before. Is it permanent? Even if it were clear and it were permanent, one would need to ask whether there was capacity in that particular decision and circumstances, because whilst all of us may have a capacity for some decisions in some circumstances, most of us, including the people that we are most concerned about, clearly would have capacity for some decisions. Therefore, there is a constant burden of responsibility on both informal carers and professionals to apply that sequence of tests. What about fluctuation? In fluctuating conditions there is perhaps an even greater burden on the person to ask whether the decision can wait. If the decision can wait, one should do so. If the burdens and costs of waiting are bearable and the person might well have strong feelings about it, it is better to wait in that situation.

The Committee suspended for a division.

Q730 Baroness McIntosh: I wanted to pick up this issue of those who appear to lack or do lack some capacity but can, with help, be brought to a position where they can make decisions. It was put to us yesterday that, on a lot of occasions, people are denied the right to take decisions on their own behalf because what is required in order to help them to do that is a great deal of support and time. I wonder whether you could tell us whether you believe that the Bill will in time be supported with the degree of resources it will need in order to make its aspirations achievable?

Lord Filkin: As you know, the government cannot introduce into a House a Bill without having clarified the financial resources to support it. That is what we have to do. In clause 2(3), a person is not to be treated as unable to make a decision unless all practical steps to help them do so have been taken without success. With care and patients, the level of

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ability to get people to participate in decisions or to make decisions themselves has moved very considerably over the last 20 years. This all takes time and that has an implication for resources. In part, that is what best practice in care professionals will be doing already. That would be the ethic that we would expect social workers and doctors to operate. Part of our assessment on resourcing will be to what extent best practice is currently met or if there is a gap between average and best practice.

Q731 Baroness McIntosh: One of the reasons why best practice might not be achieved in comparable areas, we have been told, is that there simply are not enough people with the relevant skills. It is at least possible that part of the reason why there are not enough people is that there is not enough money to pay for those people to be trained, or for people who have some skills to acquire others. The question of putting resources into creating resources is going to be as important as funding directly the particular provisions of the Bill.

The Committee suspended for a division.

Ms Winterton: We are looking at some of the long term implications particularly for health and social care staff, regarding implementation and the likely training to be required. The codes of practice that were issued by the Lord Chancellor's Department as was, when I was there, have gone some way to raising awareness about the issues of incapacity, how to assist people in making decisions, recognising the fluctuating capacity considerations. Obviously, that will change when the Bill is passed but there is that increased awareness which is quite helpful, particularly in terms of training health and social care staff. It is difficult to give, particularly at this point, precise estimates of cost but what we have tried to do is to put together a model to see what the transitional and longer term costs would be. Perhaps I can go into a little detail about how we have done that. What we have tried to do is, first of all, work with policy experts, stakeholder organisations, health and social care professionals. We have said, "Can we assess from your point of view the likely impact of the Mental Incapacity Bill?" We look at the work they currently do and see how that will be increased or whatever by the demands of the Bill. We have also had workshops in various places like Birmingham, London, Cardiff and Manchester to work with those individuals to say, "Let us take this down to practicalities and see what else you need to be doing. Let us look at any additional demand. Let us look at the type of training that would be necessary to do that." We have also looked, where we know there is best practice at the moment, at how in the meantime that could be spread so, where we know that people are working to the high standards that would be required under the Bill already, we can then make an assessment from that as to likely costs. What that is showing so far is that we do need to look at some of the other assumptions as well—i.e., numbers of people who may be involved in the care and training that perhaps is already available, for example, and how we need to enhance that where

there are other training opportunities that it can be linked into. We are trying to get a much clearer idea of what we would be looking for in terms of those staff members and workers in the health and social care field.

Q732 Mrs Browning: Have you calculated what the costs would be if a facility for independent advocacy was added to the Bill?

Ms Winterton: No, except that in terms of the range of decisions that are going to be taken under the Bill and obviously the numbers of people that would be involved, quite frankly, it would be extremely difficult to envisage that there would be the scale of resources available. My impression as well would be that it is not always applicable in individual cases. There may be people who feel that is not appropriate for them individually. To say that we could look at the whole range of people who would be covered by the Bill and imagine that in every case there may be an advocate would be unrealistic for us.

Lord Filkin: I think I would emphasise "undesirable" also because there are very many situations in which there is not a need for a formal advocate. There are other situations where there might be.

Q733 Mrs Browning: You will be aware that various groups who have given evidence to this Committee, not just the people themselves who might have their capacity analysed, have made the case that in order to bring balance to those people whose capacity is being questioned independent advocacy would give the balance to that individual which they feel is tilted in favour at the moment of carers and professional staff. I hear what you say about the need to train and provide professional staff, but unfortunately in many practical examples one can think of right across the board, whether it is learning disabled or elderly, it is challenging what professional staff believe the right thing to do is for that individual that requires the input of independent advocacy. If this is not to be a charter for statutory services but is to be a charter for the individual and that independent advocacy facility is not there, it could leave this Bill subject to the criticism of not really being balanced in favour of the individual.

Ms Winterton: There is increasing support being given to advocacy and, through things like *Valuing People*, we have tried to increase that. There is a clear commitment to do that in appropriate circumstances, but I would come back to the point that Lord Filkin made that it is not in every one of these situations that it would be appropriate. Where there is increasing provision, that may well be used, but it would just be impossible to say that we can guarantee that in any one of those situations it is possible.

Q734 Mrs Browning: One of the difficulties with advocacy for anybody who is subject to decisions being made about them is that there is a real problem between the advocate being the same person who is employed by the statutory services who holds the purse strings and knows what the availability of

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choice is. For example, I do not believe social workers can truly be proper advocates for the individual because they are in the pay of the body that determines what is and what is not available. It is that problem that still exists now but which we also come up against, not in every case, but in many cases in this legislation.

Ms Winterton: Yes. I think though that, at the same time, you could look at some of the safeguards that will be there through things like the Court of Protection. In this circumstance, you would perhaps be looking into a deputy if it was not the person who had the lasting power of attorney. You are talking about somebody who is able to undertake the care of the person but who is an independent person. In those circumstances, there is of course the safeguard of being able to make an appeal against the decisions being made.

Q735 Baroness Fookes: In an informal situation, what steps might a concerned outsider take if he or she felt that the best interest principles were not being observed?

Lord Filkin: They would have a number of recourses, partly depending on location. If, for example, they thought a residential care setting was not appropriate for a particular person, there would be a range of locations they could raise that complaint to.

Ms Winterton: I did not realise what you were getting at. I thought you were talking about the court procedure.

Q736 Baroness Fookes: Let us start from the first principle: a concerned outsider is worried. What is the first step he or she would take?

Lord Filkin: You would go to the most immediate point of redress rather than jumping into court, for all sorts of common sense reasons. There is a range of complaints mechanisms in social care and health when individuals feel that someone is not being appropriately treated. These have been substantially strengthened in recent years.

Ms Winterton: If you were thinking in a wider sense perhaps of something a bit more sinister, where there was worry about abuse, I would draw attention to the "No Secrets" statutory guidance which we at the Department of Health publish, which is about the protection of vulnerable adults and which requires local authorities to set up a multi-agency approach for dealing with complaints of that kind.

Q737 Baroness Fookes: One would go to the local authority or specifically the social services arm of the local authority?

Ms Winterton: If a person was a deputy or had lasting power of attorney and they were complaining about the type of care that had been given to the individual who did not have capacity, there would be things like the patient and liaison service in a hospital and ICAS which has been set up to deal with specifically NHS complaints. There is also CHAI, the inspectorate, which would look at the various areas as appropriate. That would be the situation whereby one would complain about the type of care

that had been given. Going wider than that to the point about abuse, you hear something going on next door that makes you feel there is something going on that you are very uneasy about. That is why the "No Secrets" guidance was published and sent out, so that within each local authority area there would be established a multi-agency approach. Many of them have used adult protection committees to bring together people from the different agencies so that they have a recognised and agreed strategy for dealing with such complaints.

Q738 Baroness Fookes: Are you satisfied that there are sufficient staff to enable this to happen in practice?

Ms Winterton: Certainly it is something that we need to keep under review to make sure that the committees are working in the way that we would like them to. That is an ongoing commitment. Some of the local authorities will approach this in different ways. Some of them may be doing it with different time constraints. As a last resort, the Court of Protection also has powers to order where a person's best interests would lie in the previous situation that you were referring to.

Q739 Chairman: I would like your views particularly on euthanasia and past decisions. I am sure you are aware we have had a very large amount of evidence on the subject. Can more be done to assuage the concerns of the many who see this Draft Bill as proposing euthanasia by the back door? Should a specific exclusion be written into the Bill? Are other safeguards needed? Is there a need to look again at the definition of "treatment" or to define "basic care"?

Lord Filkin: We have been surprised by the extent of representation made about euthanasia under the Bill. Because of that, I wrote to MPs and peers to find out what was the position, firstly emphasising the aim of the Bill is to empower adults with mental incapacity to make as many of their own decisions as possible and, where this is not possible, to ensure that there are safeguards to protect them. Doctors are always obliged to act in a patient's best interest. Sometimes that will mean that more futile treatments are not given. However, euthanasia is quite different. It is a positive act carried out with the intention of ending life. The Bill contains no definition of euthanasia because it does not concern euthanasia. In a sense, it is quite difficult because I think some people do wish to believe it is about that; whereas it seems to us the Bill is not about that. I think all we can do is to keep on trying to find ways of saying that very clearly. The point is euthanasia is against the law and the government has no intention whatsoever of changing that position.

Baroness Knight of Collingtree: Indeed, there is reason for concern because what is already happening is quite clear. Patients are being denied food. You could say that it is not a positive action not to give food. I hope that is not the response. Certainly time and again it is on record now that patients in hospital are not being given the

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necessities to keep them alive. The fact that the Bill does not really address this clearly is what has given cause for the concern expressed.

Q740 Baroness McIntosh of Hudnall: Could I tie this together with the advance decisions, because I think that is where the difficulty comes. If somebody has made no statement as to how they wish to be treated and they are ill and incapacitated, a different set of priorities applies in the sense that it is absolutely essential that doctors act in the best interests of their patients and that should apply in all cases. However, if a patient has made an advance directive to the effect that he or she does not wish to be treated, which apparently is provided for in this Bill, the issue about euthanasia comes up because euthanasia, as I understand it, is not about people being brought to their end without their consent. It is to do with people being brought to their end with their consent. The advance directive provision implies or could be thought to imply consenting to having one's life ended as opposed to consenting to not receiving treatment. I know there is a difference and the Bill intends there to be a difference, but it is a difference that is in some cases hard for some people to discern. I do not include myself. I think I understand that the Bill is not intending that, but there is a great deal of concern that it is.

Lord Filkin: I am not sure that facing two problems at once helps or hinders. Let me have a go. When a person has an advance directive that, for example, if they are seriously ill it is clear that no ongoing medical treatment will be able to cure them and they do not wish to have doctors or hospital wards officially striving to keep them alive through artificial means, in that situation it is clear. I think that is a situation that very many people in their ordinary lives do feel. The reverse also would apply, would it not, if a person had made a reverse advance direction and they did not wish always to have continuation of artificial nutrition? That was their judgment on whatever grounds, ethical or religious; that was what they wished. In that situation it would be clear. Staying with the artificial nutrition and hydration, because that is probably where the debate is, the middle ground, the most difficult ground, is where there has been no advance directive either way and it is as clear as the doctors think that there is no possibility of cure and yet artificial nutrition and hydration is sustaining the person alive. There are two responses to that. First of all, the House of Lords has made a judgment which we respect. It has made a judgment that in the *Bland* case it was proper to end the artificial nutrition and hydration because that was seen as medical treatment. That was their judgment. I am not in a position to argue with it. We would say that, in situations like that, if there was doubt or dispute then the doctors should take that issue to the Court of Protection for a decision, particularly if there was any whiff of dispute between what the doctors thought and what the relatives thought. That is exactly, of course, what the Court of Protection is there for, a more accessible form of dealing with the most difficult issues. Of course, a decision has to be made one way or other, either that

one continues the artificial nutrition and hydration for what might be 20 years or that someone makes a decision not to. The House of Lords decided that the decision in those circumstances to end it is not euthanasia but is the ending of medical treatment and we respect that position, but when in doubt the Court of Protection has to arrive at a decision in that situation.

Q741 Baroness Knight of Collingtree: But is it not very important to get on record that the Law Lords who made that decision made it also very clear that it should not be used as a rule by which things of that kind happened in future and that one of the Law Lords said, "This now leaves the law in an impossible position"? It should not surely be used as a yardstick now that that is what happens in cases like *Bland* automatically?

Lord Filkin: It certainly only applies as a judgment around PVS cases. If another case comes up in a similar context then House of Lords judgments carry precedent and need to, for good reason; otherwise we would always have to go to the highest appellate court in the land.

Q742 Lord Rix: Would you not think that the very phrase that is being used at the moment, "advance refusal of treatment", gives people the feeling that this might be a long-distance form of euthanasia? To refuse treatment is rather a negative way of putting it. I am certain you could write "advance statement on treatment" or "decisions on treatment for the future", and I believe you could write the advance statement or decisions in such a way that any implications of euthanasia would be totally excluded from the wording and the possibility of construing that thought. Can you tell me why advance decisions to refuse treatment actually found their way into the draft Bill anyway, because I gather that the Lord Chancellor's earlier policy statement "Making Decisions" felt that such provisions were unnecessary?

Lord Filkin: At one level and one particularly these things are covered by the common law. What we have sought to do in the Bill is try to give as much appropriate certainty as we can. I think the argumentation about that would be in essence that here today, if I am assumed to have capacity, I can make the decision that I do not wish to have medical treatment. That has been a fundamental principle that effectively stated that not anyone else can force medical treatment on me if I do not want it. If that is right, and I think it is right, then the reason for putting something in the Bill about it would be, why would somebody who had lost capacity or knew that they were going to lose capacity not have the ability to express their wishes if they felt strongly about it? No-one says they have to express those wishes but the Bill gives them the power to do so if it is something about which they feel strongly.

Ms Winterton: Maybe I ought to come in here a little bit as obviously the question you ask is about why the decision was made to put it in. The difficulty was that if you left it out there would be a bit of confusion as to how that might relate to lasting powers of

attorney and general authorities in the Court of Protection, so we felt at the time that this would be a helpful clarifying measure to include.

Q743 Lord Rix: Would you not agree that the wording "advance refusal of treatment" is perhaps a little pejorative and might make people retreat from the idea? I would rather place on record how I would like to be cared for in my last days rather than how I would like my life to be terminated in my last days.

Ms Johnston: There might be an issue about legislative provisions, which is what these clauses are trying to do, make clear what the legal effect is of a particular sort of decision. That may be one clause in a much longer document, much of which would not qualify as an advance decision, but what it was thought important to resolve was that if something that is a qualifying advance refusal has been made people need to know what effect that has on the other decision-making structures within the Bill. I do not think there is any suggestion that you could not make something still called a living will or an advance statement. What the clauses are trying to do is say that if bits of those things include advance refusals of treatment, then here is the legal consequence of that.

Lord Filkin: There is also perhaps a distinction, I have been reminded, between advance refusal, where we have a right to refuse treatment, and demanding certain treatment. We do not have the right to demand treatment. We can request it but it is not categoric that doctors or hospitals are forced to follow literally a request for treatment A as opposed to treatment B. In a sense there is a difference in the power of doing it in those two situations.

Q744 Lord Rix: In the codes of practice would there be a pro forma giving appropriate wording for an advance refusal and an advance decision? Would there be instructions that witnesses could not be members of the immediate family, could not be likely beneficiaries of the will, etc? All this, of course, would assure those who thought this clause in the Bill could possibly lead to euthanasia.

The Committee suspended for a division.

Lord Filkin: In a sense we agree that it is important that they should be kept under review and up to date, and the code would deal with this, as the current BMA code of practice does. Also, in a wider context it would be very important to have advice in codes of practice about the making of advance directives which makes the person fully aware before they do so of the importance of it, the weight of it, the context of it, so that they can think very carefully about the range of issues. The test also with this would have to be about validity and applicability. I also think, if I recollect, but I may be in error on this, that it is not utterly absolute. There has to be an ability to take into account the context of the situation at the time by right and, if there is evidence, for example, that the person who made the advance directive in terms of their previous values or statements might have taken a different view if they

had known the circumstances might change, that has to be weighed in the balance at the same time. That seems to me, although difficult, right.

Q745 Lord Rix: Would you exclude as witnesses likely beneficiaries of the will or relatives, which is normal practice anyway if you are making an ordinary will? Would it not be the practice for these advance statements?

Lord Filkin: It is normal practice, I think, is it not, and therefore we would need good reason not to, is the short answer.

Ms Johnston: I think a lot of these issues will be expanded on in the code of practice.

Q746 Chairman: Just before we leave advance decisions, we had some evidence from a number of people surprised at the terms of 23(2), which says that a decision can be expressed in broad terms or non-scientific language. The other thing that has been put is that they should be always in writing and perhaps witnessed, that they should be advisory rather than binding, and that all GPs should be required to record them in patient notes.

Lord Filkin: I understand why people made those representations, because of the potential importance of these decisions and a desirability for certainty. Against that though, which is why we certainly were minded initially (and it may still be our position) to keep it informal, was to allow what may be necessary flexibility. Frequently it is the case that people make these decisions quite late in the process, for example, before going into an operating theatre. We also do not want to discourage people from keeping them up to date by making it too formal or too bureaucratic. Having said all of that, we have got to look at this in the round to see if it is possible to strike a balance in any way better than we have done currently between obtaining the benefits of that informality without opening up the risk of abuse. It may be that it is impossible to do so, that you cannot actually meet both tests at once.

Ms Winterton: On the point of GPs, I think the difficulty might well be what would happen in an emergency situation, what if the person had changed their view but the GP had not been notified. There are some practical issues to think through.

Q747 Baroness McIntosh of Hudnall: You have laid considerable emphasis as this session has gone on on the importance of the Court of Protection and its primary value being resolving some of the difficulties that might arise as this Bill is implemented. How accessible, both geographically and physically, do you believe the Court should be and would it be able to act fast enough in the kinds of circumstances that you have described already in reply to earlier questions?

Lord Filkin: The first thing to say is that the Court of Protection is an important long stop, that it should not be seen as the court of first call. As much as possible we would want people to resolve disputes at the point of the dispute by using dispute resolution mechanisms in the context, whether it is a hospital or the GP or any care situation, for obvious

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reasons. You are more likely to get a better resolution by doing that. With regard to the specifics, the court will have a regional presence. We think it should retain the informality it currently has got. I went to sit recently in on the Court of Protection and it is quite appropriately informal, by which I mean it is sitting round a table, and that is good for obvious reasons. It will have emergency application, as the High Court has, for dealing with emergency applications, so yes, it would be able to deal very fast through emergency application procedures when it is necessary, as it must do.

Q748 Baroness Fookes: You indicate that legal aid will only be available in the new court for more serious and complex cases. How then will such cases be defined?

Lord Filkin: There are many cases when legal aid will not be needed because in many cases it will be an argument about the facts rather than about law, and many of the cases that go the Court of Protection will and should be dealt with in writing rather than requiring attendance. Also, we are cautious about seeing that involving lawyers—and I do not wish to be rude to lawyers—necessarily is the solution to some of these issues. If the person is perfectly capable of making representations themselves to the Court of Protection, as they currently do as individuals, given the context of informality, it is desirable, consistent with the principles of the Bill, that people continue to do so and one does not take that away. Also, using lawyers often can escalate issues by making them very adversarial in some contexts. Having said all of that, when it is necessary to have a lawyer put your case, because the issues are complex and they are legally complex, then the Legal Services Commission has the duty to provide people in those circumstances with appropriate legal support. Finally, the thing to say would be that the Official Solicitor himself, who is independent and an expert adviser, has also to act to represent people when he thinks it is appropriate to do so.

Q749 Baroness Fookes: The Law Society told us that they were really worried about barriers to representations, for example, the constriction of legal aid. Do you think they were overstating the case?

Lord Filkin: I think it is important not just to see funding more lawyers as necessarily the central need. In many situations it is important to provide people with information and advice about their situation and the options earlier on in the process rather than just seeing more legal aid obtained for formal dispute conflicts in the court. There is always a case made by the Law Society that it would be good to have more legal aid, and I would not want to comment on that, but I do not think that one should just see this as a debate about legal aid. It is as much a debate about getting information and advice to people at a point where they might need it.

Q750 Baroness Barker: One of the issues that has not received that much attention during our deliberations and one that I feel very strongly about

is financial abuse, of which there is a great deal. I preface my question by saying to the Minister of State that one thing that should be in the Bill is that people should think about receiving training even though the finance and banking industries were not there. I wonder if she might respond at a later date about that. I want to talk about the court-appointed deputies and how they are supervised and how their powers are reviewed. Under the existing system there is already a fair degree of disquiet, particularly about staff of local authorities, usually directors of social services, being appointed as receivers and, as increasingly they will be involved in the decision making not just about what care a person should receive but also the costs and charges of that care, there is potential for there to be a very big conflict of interest. I wonder if we could talk about that and also about expanding the role of the Lord Chancellor's Visitors.

Lord Filkin: On the first point about the avoidance of conflict, the Public Guardianship Office currently is doing quite a bit of work trying to work with banks and building societies to raise awareness of EPAs and to raise the awareness of the risks of financial abuse. I think that is very important. We need to sustain that, obviously, in respect of this Bill, because at times it is clear that they do not always understand the need for vigilance and caution in that respect. Secondly, financial directors will in a sense operate in the same way as at present receivers by the need to lodge accounts with the Public Guardianship Office which clearly has a duty to enquire into anything that causes them or should cause them concern, and also that visits by the Lord Chancellor's Visitors are an important further safeguard, to visit the situation themselves to see if they can identify any evidence of actual abuse if that was there. We currently have a retinue of Lord Chancellor's Visitors. We will need to keep under review whether more are needed in future if this work expands as a consequence of the Bill.

Q751 Baroness Barker: One of the consequences of the Bill will be that powers of attorney will cover both financial and welfare decisions. There is a great deal of concern that within the system, both informally and formally,—and I contrast your last answer with the one before about not involving that many lawyers—there is a great deal of risk that people whose ability is limited are going to be subject to decisions about their care and their finances and that all of those decisions are going to be made by the same people in many cases without adequate scrutiny. That is the real point I want to draw out.

Lord Filkin: I accept the importance of the point. Clearly, we think of the ability to have health and welfare deputies as benefits but that also, as you imply, puts in the need to have effective supervision arrangements openly, and the short answer is that I think that is an area we are still in discussion on, on how best to give effect to that, in practice, the balance between what should be done by the PGO, what should be done by a care professional,

inspection arrangements and so on at a more local level. Work is in progress on that but we accept the importance of a clear answer to that.

Ms Winterton: It goes back slightly to what I was saying earlier about the extent to which a complaint might be made, whether it is about the provision of care or whether it is something rather more which might be an abusive situation.

Q752 Baroness Wilkins: We have had disturbing evidence that some form of financial abuse takes place in about 20 per cent of cases. Do you think the Bill should be more trying to prevent that abuse?

Lord Filkin: I am not sure whether it is the Bill or whether it is we who have responsibility for trying to invigilate it more, because in essence there are already responsibilities on the Public Guardianship Office in terms of trying to identify and prevent financial abuse. It goes to the heart of their role because their role is about trying to provide effective protection. You will know as well as I do that that is not simple, by which I mean that the potential for abuse in this area is real and ever-present and one must assume, perhaps against one's wishes, that there is risk almost in any situation. For a PGO that is developing a specialist unit to investigate allegations of financial abuse and I had a vigorous session with their management board a few weeks or so ago about this where I was really playing devil's advocate in challenging them as to whether their arrangements for identification of financial abuse were strong enough. What we decided at the end of that was that we should basically involve for the Treasury an external auditor to look at their systems and processes to see whether they were as strong as they could be or should be. In a sense that issue applies now. It will apply just as much in the future but it is essentially an operational issue about trying to ensure that you have people who are very vigilant, highly suspicious, highly skilled at looking for patterns of abuse because, given human nature, there will be people who will attempt to do so, for obvious reasons. If somebody has got a lot of money it is tempting sometimes to help yourself to it.

Q753 Chairman: Is not the problem in fact that we do not actually know how many enduring powers of attorney there are? It is an unknown figure so therefore by definition any fraud or abuse is unknown. This is a problem that we hope that the LPAs will put right.

Lord Filkin: You are absolutely right. In a sense the situation of the Bill will be better than it is now because LPAs will have to be registered before they can be used, whereas with current EPAs it is difficult to monitor because they can be operated without registration.

Q754 Chairman: One view was put that the Bill should require all enduring powers of attorney to be made in the lasting power of attorney, but we are told that that is a practical impossibility.

Lord Filkin: I think that is probably true.

Ms Winterton: From the health care side it may be that people might want different attorneys for different decisions. Somebody that you trust with your finances may not be the same as somebody that you wanted to make decisions about your health and welfare.

Q755 Laura Moffat: The Bill is very clear about ensuring that people who are found to be abusing vulnerable people who lack capacity will receive punishment for that. Do you think that there may be value in adding to this Bill an inspection process so that the local authority or any other body may be able to inspect and threaten to inspect and therefore prevent or deter abuse rather than trying to stop it when it has occurred? Is there any value in that being put into the Bill?

Ms Winterton: We would have certain difficulties in that, although we are looking at the way that there could be a protection of vulnerable adults list and that would as well put a kind of workforce ban on people who had shown any sort of abuse before. There will be the systems that I have outlined before in terms of care homes, for example, inspection, the new CHAI taking over inspection, and the committees that I talked about in terms of the multi-agency approach that local authorities will be expected to undertake under the "No Secrets" statutory guidance. I know there have been some calls to have a similar system as for child protection but I think the overall message we are getting, including from many of the stakeholder organisations, is that that might be overly intrusive and that carers and families might feel that that was inappropriate in those circumstances. What we want to try to do is to concentrate more on the safeguards for people as opposed to having the more interventionist and perhaps intrusive systems that have been mentioned in terms of making it very similar to child protection committees.

Laura Moffat: So "no" is the answer.

Q756 Baroness Barker: Your paper suggests that the new non-statutory Adult Protection Committees to be set up by councils with social services responsibilities will take the lead in protecting vulnerable adults from abuse, but the Association of Directors of Social Services told us that many local authorities have yet to see these committees and might not give priority to this unless placed under a statutory duty to do so. Would you consider making it a statutory duty to do so, and have you reflected on the impact on local authorities from the point of view of their budgets, bearing in mind that they do have to provide for their statutory obligations in advance of anything else, given the pressures they are under at the moment?

Ms Winterton: We understand that something like 90 per cent of local authorities have Adult Protection Committees either up and running or planned, and we obviously see that as a very good way of taking forward the statutory "No Secrets" guidance which, as I say, did require local authorities to look at how complaints could be made

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in this area. Having said that, we will continue to monitor the effectiveness of the committees and if we feel that there does need to be a strengthening of it we would obviously look at that very seriously.

Q757 Baroness Barker: Can you explain, Minister of State, how Adult Protection Committees would differ from Area Child Protection Committees that have just been abolished with the introduction of children's trusts? What is the distinction?

Ms Winterton: This is for vulnerable adults.

Q758 Baroness Barker: I understand the client groups are different. What is the distinction in the model? Are we taking a model that has not worked that successfully for children and applying it to vulnerable adults or are we applying something different?

Ms Winterton: I must say I could not tell you the exact difference in terms of the constitution. I am quite happy to write about the difference between the two if that would help. Again, just to emphasise, we certainly feel that this is something that we will keep monitoring to make sure that they do have the powers necessary and that they are being set up in the areas as we have requested.

Q759 Laura Moffat: Naturally there is concern around the issue of medical research for those who are not able to give their own consent. The Medical and Psychological Society has given evidence to us and has raised concerns about that because it is very important that research goes on for things like Alzheimer's Disease to ensure that we are able to continue to be able to make medical strides in those areas. What protections are there not only for the people who may well be involved in medical research but also those who undertake that research?

Ms Winterton: The Bill itself allows medical research to be undertaken on somebody without capacity if it is felt to be in that person's best interests. Obviously, it would be very controversial to include research that was not in the person's best interests. However, if there is a feeling that on the one hand the provisions at the moment might be overly constraining as they stand, and if there are felt to be further safeguards that need to be built in on either side, then we will be happy to hear those representations and ideas and give them very serious consideration.

Q760 Baroness McIntosh of Hudnall: Can I just pick up one issue? You talked about research being in the best interests of a patient before it can be legitimate. It was put to us by the witnesses that have already been referred to that the definition of "best interests" could be extended to include the wider interests of that patient, such that, for instance, with research leading to treatment improvements that would not benefit the patient directly but would benefit, say, that patient's family, let us say, the discovery of genetic defects that could be corrected, the use of "best interests" in that context might be suitably extended to allow that kind of research. I am choosing my words rather carefully because what

this seems to me to indicate is the extraordinary plasticity of the notion of "best interests" which has come up a number of times in the evidence we have heard. First, can you comment on this question about research and it not being directly in the interests of the individual patient and, secondly, does it give rise in your mind to any thoughts about best interests and whether or not it needs to be tied down as a concept rather more firmly than it presently is within the draft Bill?

Ms Winterton: Let us take an example. I am trying to think it through. If there was something which meant, for example, that the person's carer would perhaps otherwise not be able to care for them any more and they might die, and there was research which on the one hand did not harm the person but might in the overall sense allow them to maintain the lifestyle where they were happy where they were being cared for, is that the kind of area that you would define as in the person's best interests? That might well be the case. If it was that the medical research might allow the carer's children, say, to have a benefit in the future for their own children, then you are getting further away, I would have thought, from the person's best interests. There is a whole series of ways that I would suspect it is quite difficult to tie down to individual circumstances and would perhaps be something that would be looked at in codes of practice as opposed to trying to define something on the face of the Bill. Those are the kinds of areas that you would start to take into account when you were looking at trying to define best interests.

Q761 Baroness McIntosh of Hudnall: The Scottish Bill does not talk about best interests. It talks about actions which are directly beneficial or of benefit to the person about whom the decision is being taken. In this particular area of research, if the Bill stated that decisions had to be directly of benefit to the person it would be pretty clear that something that was not directly to their benefit would not be acceptable. That is why I ask you whether this particular issue does allow reflection on whether "best interests" is sufficiently robust as a definition or whether it should be qualified in some way, as has been suggested by other witnesses.

Ms Winterton: I suppose you could interpret "direct benefit" in the same way too. I would have thought that in the instance that I have given back you could see that one situation was a direct benefit; the other was not necessarily a direct benefit at all, and therefore I am not sure that "best interests" does not cover it adequately. As I say, if it is felt that there is a need for greater safeguards we would certainly look at that and hear what the Committee had to say.

Q762 Baroness Knight of Collingtree: Is it not the case and ought not it always to be borne in mind that the whole business of using incapable or possibly sub-standard people to do research on is something which strikes a chill in many a person's hearts? I think one of the difficulties here is that to try and assess the words that you used, Ms Winterton,

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“harm” and “best interests”, is capable of all sorts of different constructions. What might be the best interests in the mind of a doctor with regard to a patient might well not be that patient’s idea of what are in his own best interests. I think that the whole business of embarking upon using incapable people to do research on is fraught with danger and I would suggest that that is one of the reasons why this Bill has been criticised.

Ms Winterton: I would slightly take issue with the use of the word “sub-standard” because what we obviously have to do is make sure that in these circumstances we are treating people with the dignity and respect that they deserve as human beings. I think we need perhaps also to remember that in some of these circumstances, as people do when they are making a decision, for example, in drug trials, and certainly if there was consent from the person who had lasting power of attorney with knowledge that the person had perhaps previously expressed a desire to be or had previously been involved in such a situation, that might be an occasion where it was felt to be appropriate. In all those circumstances one would have to look very carefully at the expressions made by family members or somebody with lasting power of attorney, but if that had been something that had been stipulated previously or undertaken previously that might be an area where it was considered to be acceptable.

Q763 Baroness Knight of Collingtree: I am only suggesting that it is a slippery slope if we embark upon the concept of doing research on people who are thought to be incapable; that is all. I think that there are certain dangerous corners in this legislation that we ought to try and avoid because they will spark off trouble.

Ms Winterton: Could I also mention that, for example, research into new medicines for the treatment of, for example, Alzheimer’s Disease, will have to comply from May of next year with the EU Clinical Trials Directive. That says that people who are incapable of giving legal consent to clinical trials should be given special protection and there should be some form of individual representation of the individual’s interests. That is obviously in addition to the requirements for a positive opinion about the protocol of any such trial from an ethics committee. I think if we put those things together we do have that kind of protection there. As I said, we will, of course, listen to what the Committee says about this area.

Q764 Mrs Humble: I was going to come in after Baroness McIntosh’s earlier comments but in fact they also follow on from the debate that we have just had. In answer to Baroness McIntosh you said that you were going to look at the different elements of best interests and perhaps introduce something in a code of practice to look specifically at areas of medical research. When you are looking at these codes of practice will you also then look at the possibility of giving different weight to the elements in clause 4 of the Bill where “best interests” is outlined, because it does list quite a few different

things and it lists the individual’s past and present wishes and then goes on to say that it would be practical to consult a variety of other people. Which is likely to be more important, especially in this very delicate area of medical research, if somebody is incapable of making their own decision and perhaps has not expressed any wishes prior to it, and then the only best interest test would be the views of their carers, their family, and is that sufficient? It is these two issues. In general terms is this list in a priority order and, if it is, then tell us? Secondly, would you be looking at according different priorities to these different elements in codes of practice that you would issue?

Ms Winterton: Obviously, I have already given some of the safeguards that will be there and particularly in the wider sense with the EU directive. I also think that in terms of looking at the whole issue of best interests it could in a sense distort the priorities if there was a ranking order. What we really need to be looking at is how we promote a partnership approach to decision making that, to the extent that the individual can be involved, should be and remains at the heart of the Bill and that should be something that is paramount in so far as it is possible. In addition, there will be the need to take into account the views of, for example, whether it was relatives or a person with lasting power of attorney. Again, that would be something that we would look at, but I know that this is an area where there is a high degree of sensitivity and I think that it is absolutely right that we do give consideration to how we can make sure that there are safeguards, and particularly when considering the issue of best interests in that area. I think it is something that we do need to look at very carefully in terms of the code of practice.

Q765 Baroness Fookes: I hope I am right in thinking that a patient with capacity can take part in research which may be of no direct or indirect benefit to that patient but they are willing to participate because of the advantages for the future. That is not possible if someone lacks capacity because they cannot give consent, but it does mean, does it not, shall we take Alzheimer’s, for example, that it makes research into that which affects thousands upon thousands of people that much more difficult? Is there no way of finding a way round this for those who do lack capacity? It clearly cannot be in their best interests but is it not possible to introduce some arrangement whereby, subject to very strict safeguards, such research might be undertaken?

Ms Winterton: That is exactly what we are looking at. If we could go to an example, were there to be a drug that had been proven not to be harmful but that there was uncertainty as to whether it could improve the situation but it was only possible to test that in the situation where somebody had, for example, Alzheimer’s, then that might be subject to all the safeguards that I have laid out already. Would that be an area that it could be said may be in the person’s best interests because we know that no harm is going to be done but that there could be an improvement, so that might be an area where it was felt to be in the

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patient's best interests but at the same time I do think it is important that we look at what would happen as a result of the EU directive where an individual's point of view will be represented to make absolutely sure that there is going to be no detriment to that person.

Q766 Lord Rix: Would not a simple start be to drop the word "research"? That in itself is indicative of things that we have heard from Baroness Knight, thoughts of Hitler, experimentation, research, that conjure up rather unpleasant memories? I would have thought that if you used a different phrase like "new treatment" or "untried treatment", at least you are talking about treatment. With "research" people have horrible thoughts and I would have thought it might be a good idea to change the word.

Ms Winterton: As I understand it I am not sure the word "research" is actually used in the Bill. In terms of talking about what flows from the Bill in terms of the words that are used, we would not be able to distinguish in terms of what we were doing with one group of people who are perhaps incapacitated and use one word for them and another word for other people, because that might be considered to be rather unsound.

Q767 Baroness Barker: There is one wider point. This process is going on in parallel to the consultation on civil partnerships. Would it be agreed that there would be a read-across from any civil partnership legislation, if it were to be passed, to this Bill?

Ms Winterton: In terms of the medical side?

Q768 Baroness Barker: No, in terms of the decision-making and consultation.

Lord Filkin: I do not think we know.

Q769 Baroness Barker: Can I leave that question with you?

Lord Filkin: I cannot immediately think there is a read-across.

Ms Winterton: In terms of consultation, are you talking about?

Q770 Baroness Barker: And things like power of attorney and who is going to be consulted about decision-making.

Baroness McIntosh of Hudnall: Whose family perhaps?

Q771 Baroness Barker: Yes.

Ms Winterton: I think that is probably something which is particularly applicable in the health care setting where there are a lot of issues about who should be consulted and, for example, if the Court of Protection was making somebody a deputy or giving a lasting power of attorney, if one had not previously been made, then I would imagine that there would be quite strong emphasis, if there was civil partnership legislation, on that being somebody who would be considered.

Lord Filkin: I think we should reflect on it and see if there is anything further in regard to that and provide it by a note.

Q772 Mrs Browning: I just want to flag up my concern about this medical research. When one looks at the medical research it goes from everything from experimentation in its early stages through to experimentation which has been advanced to the point where no human trials have yet been done. We can all understand a situation where there was not a developed drug or procedure that had yet been tested on human beings and a last resort situation, and I am thinking of the recent CJD case, for example, where the opportunity to submit somebody to that is very clearly a last resort, and this general medical research experimentation which I think should surely be something which people with capacity should consent to. The idea that you would need people without capacity to consent to this seems to me quite immoral.

Ms Winterton: As I have said, I am sure that there will be those who say there are certain circumstances where an improvement could only be seen if somebody actually had the particular condition which is obviously what happens in certain cancer trials and others. That is certainly something that happens. What I am saying is that I understand that it is a very sensitive area. I understand that with all the safeguards from the EU directive there is still a very real need to make sure that it is monitored extremely carefully. We are more than willing to hear views on whether there are further safeguards that need to be built in, at the same time balancing that with the points that are made by people who feel that they have made a very strong contribution in this area, that need to in some instances be able to work in certain ways with people who are suffering from a particular condition. It may be that you could overcome some of those problems in terms of people expressing when they felt that it would be appropriate for them. In some of the areas there will be fluctuating conditions and what we must make sure that we do is take into account individual people's wishes when they may have capacity in anything that they may wish to participate in when they do not have capacity.

Q773 Mrs Browning: But that is part of a different matter. When somebody is deemed to have capacity, and bearing in mind that most conditions, including Alzheimer's, are degenerative, it is not just something that happens overnight, somebody who has capacity and who says, "If X happens to me ...", in the same way as if you left your body to medical research after you died and you take that decision while you have capacity, that is a different matter. What really concerns me is that someone who is deemed to have lost capacity is then presented by some other party as being a suitable candidate for medical research.

Ms Winterton: Supposing you came at it from the other direction when, as you say, somebody has capacity and perhaps a clinician said, "Were you to lose capacity and were we to feel that there may be

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something which could be of benefit but we are not sure; we cannot guarantee that it is; we might be able to guarantee that it will not do you any harm but we need to see whether it could improve your position". Supposing in that position somebody said that they would like to give their consent for that, then that might be something that would be considered. Against, just to emphasise this, the Bill does not allow research to take place if it is not considered to be in the patient's best interests.

Mrs Browning: I just think, Minister, that if the person has capacity when they take a decision about future benefit which may affect them, particularly if they have a particular condition which is going to follow a pretty well rehearsed pattern, that is a different matter. They are entirely entitled to take that decision while they have capacity. What would worry me is someone who loses capacity and then is considered as a candidate for medical research under those terms. Those are two quite separate things and I worry that this Bill would entrap those sorts of people.

Baroness McIntosh of Hudnall: Minister, could I say that Mrs Browning has raised a case which is of recent date which does bear quite interestingly on this. I do not think we have discussed it at all. This is the case of the patient who was recently treated with a new drug intended to reverse the effects of CJD. The situation there, as I understand it just from newspaper reports, is precisely the one that is being described, that that person has lost capacity to a very significant extent as a result of the disease and was treated, presumably with the consent of those who have responsibility for him. Perhaps you would like to reflect on what impact, if any, that case and many others like it might have on the way that research is dealt with. At the moment research is not dealt with within the Bill at all but it has been put to us that it should be and it is included in the Scottish Bill.

Q774 Mrs Browning: If I may just say, that was a last resort type of intervention which could quite clearly, if it worked, be seen to have benefited that particular individual when all else looked as though it had failed. There is a difference between that and in someone's interests which might be of use in ten or 20 years' time to somebody else.

Ms Winterton: Obviously, what we are seeing here are the very real fears that are around this issue, which is exactly why it is not in the Bill, but of course we will take back the views that you have put forward.

Chairman: I think we have reached the point now where we should finish. I am extremely grateful, Lord Filkin, Minister. You have been very patient with all the interruptions and divisions. Although we have touched on "best interests", general authority and resources throughout the whole of the session, it would be helpful if you could write to us with specific answers on the questions which have been given. They are number 7 on best interests and number 8 on general authority, and at the end on resources.

Baroness Barker: Could I ask, when you respond to question 8 about general authority, would you say more about your plans for appointeeships and particularly you might like to include colleagues from the DWP in that respect.

Q775 Chairman: We are extremely grateful to you both. We were given a very tight timetable by Parliament, as you know. We intend to meet the timetable and we will be producing the report by the end of November.

Lord Filkin: Could I thank you for the expertise that you have brought to this. We will be pleased to respond as fully as we can to those questions and any others that, upon reflection, come to you in the next few days.

44. Supplementary memorandum from the Lord Filkin (MIB 1221)

Thank you for your letter of 23 October following the oral evidence that Rosie Winterton and I gave to the Joint Committee on 22 October. I am now writing to provide you with additional written information that we were not able to cover fully at the oral evidence session due to pressure of time.

First, I attach answers to the questions about Best Interests, the General Authority and Resources that we did not reach. On Resources you are aware that when the draft Bill was published it was accompanied by a *partial* Regulatory Impact Assessment. This is in accordance with Cabinet Office guidelines issued by the Regulatory Impact Unit. The RIA is in a partial form only because it reflects the consultative nature of the scrutiny process. A full RIA is required for introduction of the Bill when the legislative proposal is firm and it is at this stage that Treasury expect us to have full costings and a commitment to absorb the costs. My Department, together with the Department of Health, are working to further develop the costings and we will be able to produce the full RIA when we have received, and taken into account, the recommendations of the Joint Committee.

Second I attach more information in relation to Baroness Knight's request for reassurance on how the Bill will affect those who are in a similar situation to the recent case of Olive Nockels as highlighted in the Daily Mail on 10 October.

Third, I attach additional responses to Baroness Fookes' questions about the possibility of including a free-standing statement of principles in the Bill and to Baroness Bakers' questions about civil partnership legislation.

Rosie Winterton will write to you shortly providing additional information on the difference in constitution between Adult Protection Committees and Area Child Protection Committees and on the Bournemouth Gap.

Officials are checking the transcript of the evidence session and will be in contact with you about any comments we would like to make. Officials will also be writing shortly to answer your more technical enquires on jurisdictional issues, data protection and confidentiality.

If, in drafting your report, you have any further queries please do not hesitate to contact me. I look forward to seeing the conclusions of the Joint Committee.

I am copying this letter to Rosie Winterton.

October 2003

Annex 1

Remaining Questions as requested by the Joint Committee

BEST INTERESTS

The Joint Committee requested the Minister's response to Question 6

Q. Is the Bill's definition adequate and readily understandable?

A. From both the oral and written submissions that have been given to the Committee, I think it is clear that it is very difficult, certainly in statute, to state by reference to any abstract criteria, what is in someone's best interests. What is in one person's best interests may be very different from another person.

This is why the current definition at clause 4(2) (b) stresses the need to involve the individual in the decision as much as possible. I think that the individual him or herself is often the best judge of what is in their best interests. This should be the starting point for any definition.

We have proposed a checklist approach in the Bill setting out the key factors to consider in determining best interests. The Code of Practice would provide more detail on how to approach best interests. It may be, however, that we need to add to or amend the checklist on the face of the Bill and we are happy to consider proposals on this.

Q. What do you say to those who want the word "personal" added, or the concept of "benefit" introduced?

A. I think that this is probably a question of semantics and am unsure how adding "personal" would improve matters. I can see that some stakeholders have concerns that the best interests of the individual may be overridden, for example, by the interests of family members.

Our intention is precisely to give primacy to the personal interests of the individual. I think that must be right. This is, perhaps, something that could be made more explicit in a statement of principles at the head of the legislation. I should also point out that the Bill does say, in clause 4, that a decision must be in a person's best interests. This is intended to be just as strong a statement as "personal best interests".

R. Should the Bill provide scope for weighing conflicting interests or prioritising the different factors involved as a means of resolving conflicting concerns, such as the possible conflict between a person's expressed wishes and what others may perceive to be their "best interests"?

A. We want to promote a partnership, consensus approach to decision-making on behalf of adults who lack capacity. I believe that creating a rank order of factors could work against this. I think it is also the case that different factors will necessarily have different weight in different decisions. The important thing is that we resolve conflicts and disputes as to which factors take priority by having everyone focused around the best interests of the person concerned. The Code of Practice will provide more detail on how this is to be achieved.

Q. And should the Bill specify more clearly what needs to be done to help overcome communication difficulties or provide better information?

A. Clause 2 (3) requires that "all practicable steps" be taken to help a person make a decision and this would of course include communication. This is a key principle of the Bill which will be backed up by the Code of Practice. I would expect to see this particular part of the Code of Practice subject to quite regular review so we can reflect changes in communication techniques.

As regards specifying communication techniques more clearly, I think that there would be too many different situations where this situation would apply to effectively specify in any detail in the Bill. However, if the Committee considers this important we would be happy to look again at strengthening this key principle in this Bill.

THE GENERAL AUTHORITY

The Joint Committee also requested the Minister's answers to Question 7

Q. Is the concept likely to be clearly enough understood by those who are likely to have to apply it?

That is a difficult question and I know that some of those who have given evidence to the Committee have not understood the purpose of the clause.

The purpose of the clause is to provide clarity on the informal powers available in helping those who may lack capacity. It is bounded by the principles in the Bill—that the other person must first be assumed to have capacity for the decision and that decisions must be taken in the best interests of the person. It must always be remembered that the person providing care can only do things that it is reasonable for them to do given their relationship to the incapacitated person. For example, it would be reasonable for a dentist to provide a person with dental treatment but not an informal carer.

I want to emphasise that the general authority does not give anyone “carte blanche” to take decisions for anyone else. Instead, it aims to replicate the current common law position.

Q. Should a clearer distinction be made between “day-to-day” decisions and those likely to have what one of our witnesses has described as being likely to have “substantial impact”?

The principles underpinning the Bill such as the best interests criteria and the general authority apply to all decision making. The Code of Practice and guidance will set out different types of decisions that may need to be made on behalf of people lacking capacity and how these should be approached.

In clause 26 we do set out some very black and white things that are not permitted under this Bill such as consent to marriage and divorce.

However, more generally it would be very difficult to make a distinction between types of decisions on the face of the Bill—after all “day to day” decisions can have a very “substantial impact”—where do you draw the line? A decision about going to a day centre on one particular day or another might not seem significant to the day centre manager but could have a substantial impact on the individual concerned.

Q. Should more restrictions or safeguards be included in the Bill?

A The challenge in legislating in this area is to strike the right balance between safeguarding protection and not over-burdening decision-making with bureaucracy.

We have sought to strike that balance by providing for a general authority that has its place in a comprehensive legal scheme. Further details will be set out in a code of practice. Given the vast range of different situations and different steps that will be covered by this Bill, it is difficult to provide for appropriate procedures and safeguards in every case. What is appropriate for a professional healthcare situation may not be appropriate for action in a private home. What we have attempted to do is to lay down principles and parameters in the Bill that allow flexibility and the code will then go on to describe the kind of processes and safeguards that should be used in different types of situations.

The draft Bill sets out a process that, in itself, provides safeguards for the incapacitated person and ensures that decisions are taken in a clear and transparent way.

First, a carer must have a reasonable belief that the person lacks capacity. This is an objective belief. It would not be enough for a carer to say “You look incapable, I’m making this decision for you”. The starting point is always that the person has capacity. Carers will have to show that they have reasonable grounds for believing the person lacks capacity in relation to the particular issue, which means they must have taken all practicable steps to help the person make the decision for themselves.

Second the action must be reasonable for the particular person to take. “Reasonable” is necessarily very wide because it has to cover all steps that could ever be required to be taken for someone else. But “for the particular person” is an important qualification—what is reasonable for a son or daughter is not the same as what is reasonable for a doctor or nurse. The Code would provide more information on what is reasonable. This will obviously be very important.

Finally the action taken by the carer must be in the best interests of the person lacking capacity. Here the carer must follow the best interests checklist—including considering the wishes and feelings of the person, consult with others if appropriate and take the least restrictive decision possible.

Q. One witness has suggested that for some decisions a second opinion should be required, as in the Mental Health Act, 1983. Do you agree?

The Code of practice will give detailed guidance on the circumstances where a doctor or other health professional should obtain a second opinion. However, I don’t think that an actual requirement for this to happen in certain circumstances would be either achievable or desirable on the face of the Bill itself.

To give you an indication of the circumstances where the Code of Practice may advise that a second opinion would be helpful, the British Medical Association has already produced guidance in this area and we envisage that the Code of Practice will follow this closely.

Circumstances where a second opinion would be beneficial are likely to include:

- where consent is needed for a particularly serious or complex medical procedure or where the consequences of that procedure would be potentially serious for the patient;
- Where it would be helpful to get the opinion of a colleague from a particular medical discipline for example an occupational therapist or psychiatrist;

Where there is doubt about a patient's capacity.

BENEFIT APPOINTEESHIPS

The Committee requested additional information on the system of benefit appointeeships and how they relate to the draft Bill.

Q. How does this part of the general authority (expenditure incurred as part of the general authority) relate to the benefit appointeeship scheme?

Benefits appointees will continue to be appointed under social security legislation rather than under the draft Bill. However, my officials will continue working with colleagues in DWP to ensure that all elements of the draft Bill sit comfortably with the procedures that they already have in place for dealing with benefits.

The appointeeship scheme carries with it a separate set of safeguards outside of the Bill to ensure that potentially vulnerable claimants are protected. In particular, the scheme provides for an appointment to be revoked at any time and for any reason. In practice, DWP will revoke it where there is evidence that the appointee is abusing their position. This will generally concern the mishandling or misspending of the benefit money itself.

Where the evidence is clear the DWP is quick to act, but it must be remembered that if an appointee is revoked then someone else has to fill the void or the claimant is left helpless. It is a situation that has to be handled very sensitively.

We are seeking to suggest to DWP that they include an obligation for appointees to spend the benefit money in the person's best interests. This would increase protection for vulnerable claimants and create a direct link between a key principle of the draft Mental Incapacity Bill and the benefit appointeeship system.

Q. What about the very specific concerns about the inadequate appeal provisions for individuals who are subject to benefit appointeeships? Presently an individual who wishes to challenge the appointment can merely request that the Secretary of State exercise their discretion to revoke the order. Surely this infringes an individual's human rights under Article 6(1). An alternative remedy would be to enable the individual under this Act to have a right of access to an Appeals Tribunal.

It is my understanding that the current arrangements do not breach Article 6 and that there is no need for individuals to have a right of access to an Appeals Tribunal. It should be remembered that appointees not "forced" on claimants. DWP is generally approached and takes precautions before making appointments.

It is also important to bear in mind that without the appointee, the claimant would not be able to access the social security system. Where DWP discovers abuse, the Secretary of State is quick to remove the appointee.

RESOURCES

The Joint Committee requested the Minister's response to their question 18

Q. Given the amount of time and extensive consultation that took place before the draft Bill was introduced, why has it not been possible to provide more detailed estimates of the likely costs of implementing the Bill?

Firstly, the scope of the Bill is extremely wide. The Bill has the potential to affect millions of people in many different sets of circumstances including private care situations, PCTs, NHS Trusts, social services and court-based forums. DCA is therefore working closely with the Department of Health in order to develop estimates of the likely costs of implementing the Bill for health and social care.

This has already involved holding workshops involving health and social care professionals throughout the country in order to work through case studies of how the decision-making process would change and to assess any additional demand/cost and benefits.

Secondly, there is an ongoing need to understand the gap between current behaviour and best practice across the full scope of the Bill. This has been challenging as there is no baseline from which we can measure. Thirdly, there is no doubt that the processes of pre-legislative scrutiny and consultation will impact on costs so work is continuing on finalising costings after the Committee reports.

How soon does the Department expect to have a realistic estimate?

Work on estimates will continue after the pre-legislative process and we will take into account the Committee's recommendations. Full costings will be given to the Treasury prior to introduction of the Bill, as part of a full Regulatory Impact Assessment.

Given the scale of the Bill, implementation could not occur prior to the year 06/07 at the earliest. We therefore anticipate that funds will not be required until well within the next spending cycle.

On which Department's budget will the main impact fall?

The costs will fall primarily between DCA and Department of Health. Costs for DCA will be for the Court of Protection, the Office of the Public Guardian, legal aid and producing public information and guidance.

Costs for Department of Health will be for training and awareness raising among health and social care professionals and ensuring that these professionals meet the standards of the Bill.

There may be some very minimal costs for other Government departments such as ODPM and DWP.

As I have said, we do not envisage that implementation could occur prior to the year 06/07 at the earliest. Decisions on spending for this period will be made during the next spending review which will report in Summer 2004. How the costs fall across each of the Departments and how these will be funded will be made as part of this process.

Q. Are adequate trained personnel likely to be readily available to make it all work properly? Will there be a need for a massive public information campaign?

Training and awareness raising particularly amongst health and social care will be important because of the numbers involved, but there will also be an impact on the judiciary, the new Office of the Public Guardian and the Court as well as in Local Authorities and the voluntary sector. We have estimated that around 100,000 such professionals will need training.

In terms of guidance, the Codes of Practice setting out requirements under the MI Bill will apply to health and social care professionals and carers in the public sector, and to those in the private and voluntary sector who are providing services on behalf of the NHS/SS.

We will also need to make consequential changes to existing DH Guidance, codes of practice, forms, leaflets and procedures that are available to health and social care professionals and carers in the public sector.

Making arrangements for training and awareness raising in all these sectors will be part of planning for implementation. In particular, we will need to establish the best way to provide this training for example whether it could be joined with Continuing Professional Development.

Q. Will there be a need for a massive public information campaign?*

Yes, there will certainly be a need for a public information campaign. We will produce codes of practice, public information leaflets, website information etc. We would hope to do this gradually over a period of time as we prepare for full implementation and will work closely with interest groups to reach out to their members on the ground.

We are already working to raise awareness through the PGO and the guidance leaflets that have already been produced by DCA.

Q. Will the Bill's requirements incur significant opportunity costs on other health and welfare programmes?

People with mental incapacity form part of all health and welfare programmes and they will continue to do so following implementation.

The Bill should not require any new systems or procedures in health and welfare programmes. Instead, it should mean that a more consistent approach is taken under existing mechanisms.

We will make sure that all programmes make adequate provision for individuals with mental incapacity which may mean tweaking systems and altering guidance but this will not involve fundamental change.

Annex 2

Baroness Knight's concerns regarding the case of Olive Nockels and its relevance to the Draft Mental Incapacity Bill

The draft Mental Incapacity Bill would help in a case similar to that of Mrs Nockels in the following ways:

- Statutory guidance on best interests would mean that everyone was focused on the person themselves;
- Decision-making would be transparent and clear to all parties;
- There would be a requirement for all relevant people to be consulted when deciding a person's best interests;

- Disagreements would be able to dealt with by specialist healthcare disagreement procedures, involving all relevant people;
- There would be faster, easier access to a specialist Court of Protection so cases such as these could be resolved quickly and with the involvement of all parties.

BACKGROUND

During the Committee session, Baroness Knight raised the very sad case of Olive Nockels who was the subject of recent court proceedings. It was agreed that a fuller answer to Baroness Knight's concerns would be provided after there had been an opportunity to look in more detail at the facts of the case and how they specifically relate to the draft Mental Incapacity Bill.

We are sure that Baroness Knight, and possibly other Committee members, will be familiar with the facts of this very sad case but they are set out here briefly. Ninety-one year old Mrs Nockels had been in hospital for three and a half weeks following a stroke. Mrs Nockels, who was also suffering from dementia, was unable to speak or swallow and doctors advised that there was no chance of recovery. The healthcare team therefore took the decision to withdraw medical treatment, which included artificial food and fluids and antibiotics, from Mrs Nockels. This decision was taken after consultation with members of Mrs Nockels' family. Two of her daughters fully agreed with this course of action, however Mrs Nockels' other daughter and grandson strongly disagreed.

It is important to emphasise the factors that the health team would have taken into account in withdrawing Mrs Nockels' medical treatment. Under current common law, medical treatment is lawful if it is in the best interests of the patient. Therefore, if the treatment is not in the best interests of the patient, it will not be lawful to initiate or continue that treatment. In the case of Mrs Nockels, doctors clearly considered that the burdens imposed by providing medical treatment outweighed the benefits of that treatment to the patient and it was therefore in Mrs Nockels' best interests not to continue to receive that treatment. Medical treatment could therefore legally be withdrawn even if this resulted in Mrs Nockels' death.

The draft Bill would not change the current law as it applied in this situation. The doctors responsible for a patient's care would still have responsibility for deciding whether a particular course of treatment was in a patient's best interests. However, the Bill would clarify the legal position and would strengthen current good clinical practice by enshrining certain elements in statute.

In this case, doctors involved Mrs Nockels' family in every decision relating to her care, including the decision to withdraw treatment. The draft Bill would, as part of statutory guidance on determining best interests, make this a requirement. In addition, doctors would have to consider a 'checklist' of factors when deciding whether a certain course of action would be in the best interests of a patient. It may be that the outcome of those deliberations would still be the same, i.e. that treatment should be withdrawn but the process of arriving at the decision would be transparent and clear to all concerned.

To return to the facts of the case, following the withdrawal of treatment, Mrs Nockels' daughter and grandson applied to the High Court for an injunction requiring the hospital to immediately reinstate medical treatment pending a full hearing of the case. This was granted and treatment was restarted but unfortunately Mrs Nockels died before the full hearing could take place.

This was a difficult case because the family members disagreed about what would be in the best interests of Mrs Nockels. Unfortunately it is inevitable that even in cases of good clinical practice, such disputes will occur. As part of looking at how the draft Bill would be implemented, we are looking at how current healthcare disagreement mechanisms can be utilised in order to resolve disputes without the need to go to court. For example, there are already a number of patient advocacy and complaints procedures within the NHS that could be used to resolve disputes of this kind before court proceedings are commenced.

However, we accept that there will be some cases that are either so serious and concern such sensitive issues or that cannot be resolved in any other way that the court is the most appropriate arena for them to be dealt with. The case of Mrs Nockels may well fall into this category and, although tragic, her case demonstrates the effectiveness of our court system in responding quickly and appropriately in such serious circumstances.

The draft Bill will enable people to have even easier access to the court by establishing a new Court of Protection with a regional presence which will take over the current jurisdiction of the High Court in these serious healthcare cases. The new Court will be a dedicated forum for cases relating to how decisions are made on behalf of those lacking capacity and, as such, will have the expertise to deal with complex cases such as this. As now, cases will be able to be brought as a matter of urgency where this is needed.

Questions on Statements of Principles and Civil Partnerships

STATEMENTS OF PRINCIPLES

Baroness Fookes: Some witnesses thought it would have been better if the statement that capacity is to be assumed unless proved otherwise should be at the very forefront of the Bill, Clause 1.

Chairman: Certainly, from the evidence we have heard, the perception of the Bill might be improved if the statement of principle were actually in the Bill rather than being hidden away in the various clauses. A number of witnesses would feel more comfortable and therefore the perception would be improved.

The Mental Incapacity Bill as currently drafted does include several key principles. These are:

- the assumption of capacity;
- the requirement that capacity is to be assessed according to each individual decision to be taken;
- the requirement to take all practicable steps to help the person make his or her own decision before a finding of capacity can be made;
- the obligation for all decisions taken on behalf of someone who lacks capacity to be made in the person's best interests.

We agree that the perception of the Mental Incapacity Bill is important and we have heard that the Scottish style of a clear statement of principles in the Bill has been well received. Therefore, we are content to investigate whether it would be possible to amend the draft Mental Incapacity Bill to similar effect and give more emphasis to the principles given above. Of course, we will need to take advice from Parliamentary Counsel as to the possibility of achieving this.

CIVIL PARTNERSHIPS

Baroness Barker: Would it be agreed that there would be a read-across from any civil partnership legislation, if it were to be passed, to this Bill . . . in terms of decision making and consultation?

The MI Bill requires consultation in decision making (on behalf of those who lack capacity) with persons who have been named as someone to be consulted on the matter in question, engaged in caring for him or interested in his welfare and/or are a lasting power of attorney. These requirements form part of the 'best interests' principle—see clause 4.

The purpose of this is to try and consult as many relevant persons as necessary before making a decision on behalf of another person—including persons who are in a same sex relationship. For this reason, the Bill is left open and does not list specific persons to be consulted and so the introduction of a Civil Partnership scheme would have little impact here. A Code of Practice will give more detail and practical guidance of who should be consulted and in what circumstances.

If a person is planning ahead for a time when they may lose capacity then they can either name persons to be consulted, or go further and make an LPA. There is complete choice in who to nominate as an LPA and no expectation that this will be a partner. The introduction of the Civil Partnership scheme will not affect this.

There are however, specific minor and technical situations where the Civil Partnership framework will effect the MIB if it were to be passed.

Firstly, clause 11 of the MIB provides that where a LPA confers authority to make decisions about property and affairs—the donee may make gifts on customary occasions—which includes the occasion of, or anniversary of, a marriage. This will have to be amended to include the ceremony of a civil registration of a Civil Partnership.

Secondly, clause 26 of the MIB, lists 'excluded provisions', whereby nothing in the MIB permits a decision to be made on behalf of another person with reference to consent to marriage or divorce. Amendments will be necessary here so that consent to the formation and dissolution of a civil partnership cannot be made on behalf of another person.

Finally, Schedule 3 lists provisions applying to existing enduring powers of attorney, which will continue under the Bill. Unlike LPAs, when an EPA is registered, notification must be sent to certain listed family members including husband and wife. Introduction of Civil Partnership legislation would require an amendment here so that any Civil Partner is notified.

For an LPA, persons notified on registration are left to the choice of the donor to allow flexibility and cater for more diverse family and caring situations that exist in the modern world. Therefore it already encompasses same-sex partners and would require no specific change.

The Department for Trade and Industry published 'Civil Partnership—A framework for the legal recognition of same-sex couples' in June 2003. The Consultation period is now complete. The responses are now being considered by DTI, who intend to legislate as soon as parliamentary time allows.

Written evidence

45. Memorandum from the Association of Catholic Women (MIB 09)

On behalf of members of the Association of Catholic Women, we are writing to express our concerns about the proposals in the Draft Mental Incapacity Bill.

1. LIVING WILLS

If Living Wills, so-called, were to have legal status, the possibility for treatment of the will writer will be frozen. Between the writing of the will and the occasion of its enactment, medical knowledge might have moved on, and cure or mitigation of the condition might be possible. Furthermore, we can envisage occasions where someone who has mandated denial of treatment should a particular circumstance arise, might well change his or her mind when the circumstances in question arose, if their mental capacity allowed them to do.

2. LASTING POWER OF ATTORNEY

As we understand it, Lasting Power of Attorney will give those appointed to look after the interests of a mentally incapacitated patient power over healthcare decisions, as well as money matters. This is to allocate very large powers to the Attorney. If the "best interests" of the patient are not seen as including hydration and nutrition, it will mean that the Attorney has power of life and death over the patient.

3. ORDINARY NURSING CARE VS TREATMENT

Medical treatment seeks to cure or alleviate a medical condition which denies the patient ordinary good health. It seeks to remedy something which is wrong with the patient. Nutrition and hydration are essential for life, tout court. However good a person's health, he or she will die without them. The manner in which they are administered does not alter what they are. They are not medication. They form part of ordinary nursing care, vital for survival. Whether mentally capable or not, each of us has a right to receive such care, even if the administration of drugs is unlikely to benefit us.

Finally, we regret that the request for comments on the Draft Mental Incapacity Bill has come in August when so many people are away. The importance of this draft bill is such that we would respectfully ask for an extension of the time for submissions.

We very much hope that our comments will be taken into consideration.

August 2003

46. Memorandum from Mrs Dominica Roberts, Pro Life Alliance (MIB 16)

1. Although much of this draft bill is useful and helpful, there are several clauses which would inevitably be abused as they stand.

2. There may well be cases where the opinion of doctors or of a patient is that intrusive treatment to prolong life is unreasonably painful or disagreeable, but it should be made clear that deliberately ending a life, either actively or by withdrawing artificially provided nutrition and hydration, can never be in the patient's best interests.

3. The bias should always be that a patient wishes to continue living, unless (as with someone able to make his or her wishes known) he or she has made a very recent, clearly worded, and properly informed decision to refuse treatment, or has shown clearly that an earlier wish is still valid. Advance directives to withhold treatment in certain circumstances are obviously dangerous. It is a very common experience indeed that people think they would not wish to go on living in certain circumstances, but find that they feel differently when it actually happens.

4. The same applies to disabled people, who usually wish to go on living just as much as the able-bodied (or more, since I understand the suicide rate is lower) and are often affronted by the implication that their lives are worthless and that they would wish to die.

5. Patients and their representatives should be able to say "Please do resuscitate, or do continue the treatment". There have been several cases where medical staff have thought a patient, eg a handicapped child, not worth saving even by quite ordinary means, in spite of the parents' wishes.

6. Every single case of a decision which might hasten death should be recorded as such, and the doctor should be answerable to a specific small panel of doctors, whose job it would be to look out for abuses. Whether one thinks easy abortion a good or a bad thing, no one denies that in 1967 it was intended only for the very hard cases and is now on demand for objectively trivial reasons. It is no one's job to check whether an aborted baby was in fact handicapped, or whether a woman would actually have been likely to be harmed at all by continuing the pregnancy. Similar abuses would inevitably happen if the idea of death being in a patient's best interests was legalised.

Decisions under the bill about sterilisation or abortion should also be recorded as such and have to be justified to a panel of doctors (though we would maintain that neither of these can ever be in the interests of the patient or her baby). Information about the numbers of such cases should be publicly available and easily accessible.

7. A close companion's belief that the patient would have changed his earlier wish not to survive, or that he has done so but is unable to convey this to a stranger, should be persuasive against an earlier declaration by the patient.

8. Similarly, to an offence under section 32 it should be a defence that the person alleged to have concealed or destroyed an advance directive honestly believed the patient to have changed his decision. It is not at all difficult to imagine a situation where a long-time partner might confidently know this by signs imperceptible to a stranger and difficult to prove, hence "honestly" rather than "reasonably".

9. The draft bill in its present form encourages medical killing, euthanasia, of vulnerable patients. The alleged "safeguards" are worthless.

August 2003

47. Memorandum from Christine Hudson (MIB 20)

1. I am totally against the withdrawal of life-sustaining treatments and care, including tube feeding, to mentally incapacitated patients. Such a deliberate act is intentional killing. It is euthanasia. I disagree with Lord Filkin who has said that this Bill will provide "protection" for adults who are mentally incapacitated. Not affording someone basic care, food and water, when they are at their most vulnerable, in no way can be described as "protection". What it does indicate, at a time when the National Health Service is already groaning, and about to groan some more with a burgeoning elderly population, is that time and money expended in the care of such patients can be "better" used elsewhere. Those charged with implementing this law can rely upon the fact that this decision making process will never be challenged by the recipients of such treatment as they are not only mentally incapacitated but will end up dead as a result—an ideal situation!

2. For centuries, doctors have exercised their expertise under the directive of the Hippocratic Oath, "First, do no harm". However one tries to rationalise and intellectualise what is proposed, being starved and dehydrated to death, is a very painful experience, a barbaric practice and in total contravention of the aims of the Hippocratic Oath. We would not treat an animal like this, especially in this country, so why are we proposing to do this to human beings? It might be as well to remember that the Hippocratic Oath was formulated to combat a situation where patients no longer trusted their doctors to serve their best interests and I think it is to the shame of a so-called civilised society that such a situation will inevitably arise again if this Bill becomes law. Only in situations such as at the very end of life, when sometimes swallowing or assimilating food can be a burden, would it be legitimate to withhold food or fluids for the comfort of the patient.

3. To perceive people living with a profound disability like PVS as tantamount to being as good as dead or having "no best interests", (according to Lord Mustill, a member of the appellate Committee of the House of Lords which decided the Bland case) is so wrong. It is the stark philosophy of "survival of the fittest" being put into action. It violates every respect and dignity due to that person as a fellow member of the human race. There are few moral convictions more deeply ingrained than the sanctity of human life. Life has always been seen as a basic good and there is no stronger human instinct than self-preservation. Even the term, Persistent Vegetative State is derogatory as it implies that profoundly disabled people can be compared to vegetables. Laws are meant to protect fundamental human rights which is why existing laws have never permitted the intentional killing of an innocent person by either act or omission. If this Bill is passed in its present form, it will permit euthanasia by neglect and omission and will have started the slippery slope to so-called "mercy killings". The British Medical Association has publicly stated that it wants to extend this law to patients suffering strokes and advanced dementia and the pro-euthanasia groups are already straining at the leash. I admit that I find it hard to understand why profoundly disabled patients achieve dignity only in death. My own daughter, until last year, was a Staff Nurse on a stroke unit. She was unhappy about several decisions concerning profoundly disabled stroke patients and in one instance was reprimanded by the consultant in charge for being instrumental in getting an incapacitated patient who was being starved, tube fed. She has now left nursing to have her first baby and has not renewed her UKCC registration as she is adamant that she will not be going back to nursing.

4. If a person “ill treats or wilfully neglects” a mentally incapacitated person in their care, the Bill makes provision for that person to be punished. I see these as weasel words! Do those who drew up the Bill not see that starving and dehydrating a vulnerable person to death is in itself “wilful neglect”? Tony Bland was not, as is popularly believed, on a life—support machine at the time the Courts decided to count tube feeding as medical treatment. He was cold-bloodedly starved to death. Lord Justice Hoffman, concerning the 1993 Bland case, noted that: “If someone allows a small child or invalid in his care to starve to death, we do not say that he allowed nature to take its course. We think that he has committed a particularly wicked crime. We treat him as if he had introduced an external agency of death. It is the same ethical principle, which requires doctors and hospitals to provide patients in their care with such medical attention and nursing as they are reasonably able to give. The giving of food to a needy person is so much the quintessential example of kindness and humanity that it is hard to imagine a case in which it would be morally right to withhold it.” Lord Mustill noted that the Bland Judgement left the law “Morally and intellectually misshapen”.

5. I am most unhappy with the term “best interests” as defined in the Draft Mental Incapacity Bill. This Bill interprets these interests as the “wishes and feelings” of the incapacitated person—a very whimsical notion. I am also unhappy about the proposed binding status of Advanced Directives. I have a now elderly relative who has suffered from a personality disorder all her life. This has provoked regular periods of severe depression, leading to episodes of extreme confusion and numerous attempts at self harm and suicide. In between these episodes, she leads a normal life, living and caring for herself and helping at village events. Her periods of normality last for a couple of years at a time. When she is depressed, she feels that she would be better off dead and wants to die. I have recently discovered that in one of her depressive modes, she completed an Advanced Directive from the Voluntary Euthanasia Society asking not to be resuscitated, which she has not retracted. Under the afore-mentioned terms of this Bill, Peggy, who is now seventy five years old, would no longer be with us.

6. The draft Mental Incapacity Bill, make no mistake, IS legalising euthanasia. I believe in respect for all human life, no matter how profoundly disabled. Any act or omission with the deliberate intent to bring about the death of that person is wrong. The doctor must always seek the patient’s restoration of health, preservation of life, prevention of impairment and alleviation from suffering.

7. Before I end, I would like to register a protest at the extremely short consultation period afforded by the government for such an important piece of legislation. I am having to take time out to write this letter the day before I go off on holiday when I have many other things to do with a young family.

August 2003

48. Memorandum from Julia Goffin (MIB 21)

I wish to make the following submission on the Draft Mental Incapacity Bill. My primary concern is that the Bill contains no amendment to outlaw the withdrawal of life-sustaining treatment and care with the purpose of causing death. There is no requirement of course to provide food and fluid in the rare cases where it causes distress to the patient.

ADVANCES DIRECTIVES

1. On the subject of legally binding Advance Directives I can see several problems. When an individual signs an Advance Directive, he can have no idea what treatments may be possible or necessary. He can have no inkling of future cures. The circumstances prevailing at the time of implementation may be complex and unforeseeable.

2. Legally binding Advance Directives could lead to non-treatment of a curable illness. The patient could, due to legal restraints on treatment, end up in the very state they feared when signing the Advance Directive ie disabled (but unnecessarily so).

3. No one is required to check whether an individual was fully informed of the consequences of signing.

4. If a patient should become disabled because of failure to treat due to a binding Advance Directive, there will be no redress as the doctor is not exercising his own judgement.

5. The power to decide when the time has come for an Advance Directive to come into effect belongs with the doctor, as does the power to decide the type and extent of medical intervention that is to be withheld. This power is not restricted to “extraordinary care” but to any medical intervention.

6. A recent survey found that 71 per cent of doctors said there were circumstances in which they would wish to disregard Advance Directives.

BEST INTERESTS

1. The traditional interpretation of “best interests” has been “best clinical interests”. The Draft Bill includes in “best interests” much wider and looser considerations such as “spiritual and religious welfare” and “financial interests” or what someone imagines the patient’s interests might be. These are poorly defined, vague and subjective opinions.

2. According this re-writing of “best interests”, an argument could be put forward that a patient’s quality of life is believed to be so low that they do not warrant the protection of the law against homicide.

LASTING POWER OF ATTORNEY

1. It is to be welcomed that the Draft Bill contains a clause that will not allow non-voluntary euthanasia by withdrawal of treatment regardless of the wishes of the patients or their families. However the extension of the current remit of the Enduring Power of Attorney into healthcare decisions could prove to be very dangerous. Appointed proxies would possess legally binding powers to force doctors to kill by withdrawing life-sustaining treatment and care. Such attorneys may be unqualified and would be unaccountable.

2. The Draft Bill includes no clause establishing a system of appeal to protect the rights of doctors who may feel pressured by self-interested proxies to withdraw food and fluids from mentally incapacitated patients.

Whilst I would agree that many parts of the Draft Mental Incapacity Bill could prove very valuable, it also includes provision for euthanasia by neglect.

I cannot understand why so little time has been allowed for evidence and submissions to be sent to the Standing Committee on these most controversial and wide-ranging proposals.

August 2003

49. Memorandum from the Bishop of Wrexham (MIB 24)

I wish to express to the Committee my deep concern about the very short consultation period that is being given to the proposals on the Draft Mental Incapacity Bill. These are matters of the deepest interest for the common good, and flawed legislation could set a pattern that would be deeply damaging for the future good of society. To have a curtailed discussion about the ethics of euthanasia by withdrawal of food or water is in itself a denial of the oxygen of proper and balanced debate in these important matters.

August 2003

50. Memorandum from Dr Clare Whitehead (MIB 25)

INTRODUCTION

I am a retired Consultant Physician in Rehabilitation Medicine to West Berkshire, retiring in 1990. I held the post for 13 years, having previously worked in the Rehabilitation Centre in Oxford. I have had 18 years of looking after people who had suffered brain damage from strokes or head injuries. I therefore write my comments from the experience of working with a team of professionals to help people return to some normality of life, even if only partial recovery seemed likely at the time of admission for rehabilitation, usually a few weeks after the event. I am particularly concerned about the possibility of withdrawal of hydration and nutrition, making it legal under certain circumstances.

1. Treatment: I note that basic life support by administration of fluids and nutrition is now designated “treatment”, to be withdrawn in certain circumstances with the intention of causing death. This is Passive Euthanasia. In the case of fulfilling an Advance Directive, it becomes Assisted Suicide. Changing the terms used is merely playing with words to attempt to avoid describing such acts as Euthanasia and therefore opening a loophole for legality, so that those involved in facilitating such acts are protected from prosecution. Describing neglect as “withdrawal of treatment” does not alter the fact that it has the intention of depriving the patient of life, and is therefore Euthanasia by another name.

2. The patient's best interests: (ref: page 2, section 4 "Best interests") "Best interests" appears to be based on the known wishes or feelings of the person where he/she has the capacity to communicate these to others. According to this draft bill, if he is "mentally incapacitated" and unable to communicate, the "best interests" are supplied by those who claim to have knowledge of that person, or who have legal powers such as held under the proposed Lasting Power of Attorney.

3. Comment: This approach could be detrimental to the patient's interests:

- (a) the withdrawal of nutrition and hydration will inevitably cause suffering which the patient may not be able to communicate; and
- (b) if the patient is thought to be suffering, a lethal injection might readily be given to relieve the suffering, ie active euthanasia. Indeed this active euthanasia was carried out on a patient in Japan (reported in the daily Telegraph 11 August 2003;
- (c) the patient may not have been in this vulnerable situation before. He might feel differently now and want to reverse his Advance Directive, but be unable to communicate this to others;
- (d) diagnosis and prognosis given for his condition may be inaccurate. In my experience of caring for rehabilitation patients, it is easy to give up hope of recovery too soon. Even if full recovery does not seem likely, the patient may recover sufficiently to be able to return to spouse or family. He may become depressed by the apparent hopelessness of the situation and then fail to improve to his potential. Some patients may make an unexpectedly good recovery contrary to expectations at an earlier stage;
- (e) there is an opportunity for relatives who want to inherit to manipulate the situation to their advantage;
- (f) new treatments, advantageous to the patient may now be available;
- (g) pressure, possibly subtle and not openly expressed may make him feel that he would be burden to himself, his family, and to the National Health Service if he remains alive. Pressure on health service staff to reduce the number of bed blockers to keep up with waiting list targets, is another factor. Patients may seem to be more mentally incapacitated than they are. Expert speech and neuropsychological assessment is needed for a full and accurate diagnosis. Patients who are unable to communicate effectively may easily be assumed to be mentally incapacitated, or less mentally able than they are.

4. Some cases:

- (a) A married woman in her 30s with husband and two children, was admitted to the acute medical ward unconscious, having had a cerebral haemorrhage. She remained unconscious for several weeks and it was thought that the outlook was poor. When she recovered consciousness she was found to be hemiplegic with speech impairment. She made excellent rehabilitation progress and went home to her family with almost complete recovery.
- (b) A man in late middle age was admitted for rehabilitation, being severely disabled from multiple cerebral infarcts. (that is areas of dead tissue in the brain). He sustained many disabilities as a result, including impaired speech function and multiple disabilities of higher cerebral function. He underwent inpatient rehabilitation for many weeks with definite but only slight improvement. He and his wife, who had advanced cancer, wanted him to be able to return home to enjoy being with her in the remaining weeks of her life before she died. This slight improvement was enough for this goal to be achieved.
- (c) On TV news recently we heard of a young man who had recovered consciousness after being in coma for 19 years following a head injury! It seems that he is able to communicate meaningfully with his family members.
- (d) I have personal friends who have had three children now adults. One is severely mentally and physically disabled from meningitis at the age of three. She is devotedly cared for by her parents. From time to time she is admitted to hospital with severe chest infections. I am sure that the "withdrawal of treatment" as described in this draft bill has never been part of the equation.

5. Comments: (a) People with an illness or injury, including brain injury, need to be given time to recover; and, together with their relatives, come to terms with what has happened to them. Healing may continue slowly for months or even years. It is only too easy to hold onto low expectations of recovery when in fact the outlook may be more optimistic than expected.

6. Conclusion: (a) By now some people may be feeling that if they reach a certain level of severe disability, particularly from mental incapacity, they are considered a burden to society and not of value to themselves or their families or the society in which we live. A stroke patient that I had agreed to have transferred to the rehabilitation ward from the acute medical ward had to wait about two weeks before we had a vacancy. She told me how upset she felt because of the change in attitude of the staff, once they knew she was waiting to be transferred. She felt she was no longer wanted. No doubt the staff were under pressure to vacate beds for new admissions. The legalisation of Abortion in 1967 has no doubt been contributory to a change of atmosphere in the NHS; particularly since diagnostic amniocentesis in pregnancy became available, so that babies that were likely to be born with defects such as Down's Syndrome could legally be killed before birth. Now that many

unborn are destroyed, it is easier to consider the next stage; the Elimination of the Unfit! How this would free up blocked beds, improve waiting lists, enable hospital trusts to meet their Targets, and show the government of the day to be making improvements in the NHS. We have already killed off many of our younger generation through abortion, (by 2001 well over five million in the UK alone, apparently) so that we now have a demographic disaster. There are large numbers of the elderly, (of whom I am one!!) compared with younger people of working age who might now be providing the working force for the NHS. Therefore it might be "very convenient" to reduce the number of sick, vulnerable, aged and heavily dependent people in our society to save money and make for a more balanced population. Such considerations can work subconsciously on staff struggling to keep up with the demands on the service. None of us can escape the possible consequences of such a scenario. Any of us could become the victims. These factors need consideration with regard to the draft MIB.

- (b) What kind of society have we become? What is the value of a life? What are the underlying values that we hold and on which we base decisions on life and death issues? Increasingly we live in a society where there seem no longer to be generally held good values. These things need to be reflected upon and acted on before the death culture, increasingly prominent in our society, takes a further hold. This draft bill gives a very negative impression. We need universally available expert rehabilitation/assessment services, and palliative care with inpatient and outpatient support services. There have been significant developments in palliative care skills in the last 30 years or so, in the management of pain and distress in those in terminal illness. Perhaps if such services were more readily available there would be less pressure towards withdrawing life-maintaining treatment. It is important that patients feel valued and respected. Modern palliative care can enable them to have a positive quality of life with freedom from pain to the end.
- (c) Implications for medical and nursing practice and for the ethos of the NHS: If the proposals described in the draft Mental Incapacity Bill became law, it would completely alter the ethics of medical and nursing practice. As a newly qualified doctor in 1958, it was required that I should always uphold the principles of the Hippocratic Oath: "I will keep them (the sick) from harm and injustice." "I will neither give a deadly drug to anybody who asked for it, nor will I make a suggestion to this effect. Similarly I will not give to a woman an abortive remedy. In purity and holiness I will guard my life and art."
- (d) A modern version of this Oath (Louis Lasagne in 1964) obviously allows for euthanasia to become legalised. "Most specifically must I tread with care in matters of life and death. If it is within my power to save a life, all thanks. But it may also be within my power to take a life; this awesome responsibility must be faced with great humbleness and awareness of my own frailty. Above all, I must not play God." Apparently many medical students will take this modern version. (NOVA Online/Survivor MD. The Hippocratic Oath).
- (e) Where are our ethical standards today? The legalisation of abortion in 1967 opened Pandora's box, with regard to the death culture now so prominent in our society. Legalisation to allow withdrawal of hydration and nutrition would be a further slide down the slippery slope to fully legalised euthanasia. Our hospitals would become frightening places for the vulnerable elderly, brain damaged and severely disabled. A priest has recently told me that several people, mostly the elderly, have told him that they are fearful of going into hospital, not because of their actual physical condition, but because of "the things that they can do to you there". Relativism, in which one set of values is considered as valid as another, prevails. The goal posts are moved to accommodate new life styles. Our Western civilisation has been based on Christian values and precepts for well over a thousand years. It was from our Christian communities of the past that the care of the sick and disadvantaged was first developed until it was taken over by the state. These principles of love of God and love and care of our neighbour and the Ten Commandments that have been the bedrock of our nation until modern times, are now being jettisoned more and more so that there is no longer a stable value base in our society. St. Benedict in his Rule for Monasteries describes unsatisfactory monks who live in groups "without a shepherd": "Their law is the desire for self gratification: whatever enters their mind or appeals to them, that they call holy, what they dislike, they regard as unlawful". Our society is becoming a rudderless ship, no longer based on sound ethical values for the good of the individual and the common good. A rudderless ship is likely to end in shipwreck.
- (f) At Lourdes Shrine in the South of France where I twice accompanied pilgrimages as a doctor, values are the very reverse of what is being promoted in our society today. At Lourdes the sick are honoured and are the VIPs. There they find they are valued as individuals, however sick or severely disabled. They find a warm and loving welcome. Many return encouraged by their experiences and have a new and happier life even if a physical cure is not evident.
- (g) Finally I quote again from "St Benedict's Rule for Monasteries" (translated from the Latin by Leonard J Doyle. The Liturgical Press, St John's Abbey, Collegeville, MN 56321 1935) "before all things, care must be taken of the sick, so that they will be served as if they were Christ in person, for He Himself said, "I was sick, and you visited Me," and "What you did to one of these least ones, you did to Me."

51. Memorandum from Michael and June Power (MIB 42)

1.1 We write as the close relatives of two persons aged 54 and 68, respectively, with severe learning disabilities. For over 14 and 12 years respectively, they have lived in separate residential care homes. They can neither read nor write nor have the mental capacity to make informed decisions outside a very limited range of issues. Both have been the subject of abuse/neglect on, at least, four occasions (in total) over the past 10 years. Mrs Power has been their Court of Protection appointed Receiver since 1978.

1.2 In the light of past experience, we welcome the Draft Mental Incapacity Bill. It is an important improvement in the area of decision-making on behalf of mentally incapacitated adults; and should help clarify the present unsatisfactory legal framework. However, there are two particular aspects of the Draft Bill (or Explanatory Notes) which give rise to concern:

A. ACCESS TO PERSONAL DATA (INCLUDING HEALTH RECORDS)

1.3 Both the 1995 Law Commission Report (paragraphs 8.20 and 8.23) and 1999 Government Report Making Decisions, (paragraphs 3.7, 3.9 3.11 and 3.12) expressly emphasised the importance of providing the means by which a person's statutory rights to accessing information could be achieved when the respective person is incapable of initiating or evaluating such information themselves.

1.4 It should be noted the Data Protection Act 1998 does not make any special provision for requesting access on behalf of mentally incapacitated persons. This inequitable, and most unsatisfactory, situation has been acknowledged by leading legal practitioners (see *Community Care and the Law*, by Luke Clements, page 36, paragraphs 2.28 and 2.29).

1.5 We have direct experience of invoking the Court of Protection's assistance by way of requesting a special Order. The Court were most helpful; but, within the limitations of UK Law, were only able to issue a Direction to receive—not compel disclosure of—the documents requested (see Annex 1).

1.6 The personal records involved—including an important Abuse Report on our relative who was subjected to ill-treatment in a Care Home—were only released after nearly two years continuous legal representations; and commencement of a Human Rights Act action at Strasbourg.

The Draft Bill does not contain any express provision, as previously recommended, to overcome this problem. This is a serious omission which should be corrected, possibly, by an additional Clause to Section 17 of the Bill.

B. MISUSE OF THE TERM "CARER"

1.7 The term "Carer" has been defined in previous Policy Guidance such as *Community Care in the next Decade and Beyond* (DON, 1990,) as "a person who is not employed to provide care in question by any body in the exercise of its function under any enactment. Normally, this will be a person who is looking after another adult in the home who is . . . mentally or physically disabled . . .".

1.8 Increasingly, in recent years, the term Carer has been arrogated by professional/service provider staff; and, in our submission, misapplied to paid support staff. In turn, Family Carers/Advocates appear to have become relegated to a lower category described as "Informal Carer". It is noted that the latter term appears no less than four times (see pages 44, 47, 48 and 50) in the Explanatory Notes to the Bill.

1.9 Is a family who visits their son in a mental hospital, virtually every week of every month for over 38 years, and vigorously advocates for his interests—to be dismissed as "informal carers"?; similarly, those who struggle for nearly two years to obtain, on behalf of the mentally incapacitated person, access to the latter's Individual Care Plans/Assessments and an Abuse Report whilst living in the community care programme?

To minimise future confusion, the term "Carer" requires unequivocal confirmation in the forthcoming legislation and/or explanatory notes thereto. The role, importance and particular contribution of Family Carers to decision-making for persons with severe or profound learning disabilities should be clearly recognised.

Finally, whilst we acknowledge the Scrutiny Committee's time will be limited, we would much appreciate the opportunity to offer oral evidence in support of the above, and related, matters.

Direction to receive documents

**THIS DOCUMENT IS NOT VALID UNLESS IT BEARS THE IMPRESSED SEAL OF THE COURT
OR THE PUBLIC TRUSTEE (IN THE BOTTOM RIGHT HAND CORNER) ON ALL PAGES**

IN THE MATTER OF *(name deleted, original available)* ("**the Patient**")

IT IS HEREBY DIRECTED THAT:

Beryl June Power of 5 Groesfford Park Brecon Powys LD3 7SF the Receiver in this matter is AUTHORISED in the name and on behalf of the Patient to inspect and to receive copies of the papers and documents and other information on the personal file held by the Social Services Department of West Glamorgan County Council and to receive on behalf of the Patient a copy of the Social Services report prepared as a result of an investigation carried out in 1995 by Mr Harper in respect of *(abuse venue deleted; original available)*.

52. Memorandum from Age Concern Cymru (MIB 43)

Age Concern Cymru is pleased to see the publication of the draft mental incapacity Bill. Age Concern Cymru has been a member of the Mental Incapacity Consultative Forum and has shared the information from the Forum with the 27 local Age Concern organisations operating in Wales and members of Age Alliance Wales representing national voluntary organisations working with older people in Wales. There is recognition among these organisations that legislation is needed to provide a legal framework for decision-making where a person lacks mental capacity.

However, Age Concern Cymru is concerned that the focus of the Bill is on the court system only. No consideration is given to the powerful role advocacy can play in helping people with limited mental capacity make decisions or contribute to the decision making process. Advocates should not be a family member and have no vested interest in the decision making process. Age Concern Cymru would urge that the Bill should recognise the importance independent advocacy can play in decision making and see it as integral to the process.

Age Concern Cymru have been pleased by the consultation process proceeding and following the publication of the draft Bill. It has been helpful that workshops on the draft Bill have been held in Cardiff. This has enabled more Welsh organisations and members of the public to participate in the consultation process.

August 2003

53. Memorandum from the British Institute of Learning Disabilities (BILD) (MIB 58)

The council of the British Institute of Learning Disabilities recently received a presentation from Chris Walker from the Mental Incapacity branch of the Department of Constitutional Affairs on proposals for legislation on mental incapacity.

As an organisation which works with and for people with a learning disability we are very conscious of the shortcomings of current legislation on mental incapacity. We have followed the publication of the green paper Making Decisions with great interest and we warmly welcome the proposals, which are currently being developed by Chris Walker and her colleagues.

I know that there is considerable pressure on parliamentary time and I am therefore writing to request, that the Bill to reform current legislation on mental incapacity is given maximum priority. You and your colleagues are no doubt aware of the recent white paper Valuing People which set out the governments proposals for learning disability services. In our view, the policies set out in Valuing People can only be successfully implemented if new legislation is implemented in respect of mental incapacity.

July 2003

54. Memorandum from Dr John Scotson (MIB 62)

CARE DUE TO THE DYING

1. I write as a retired medical practitioner who has cared for many dying patients. I take a special interest in this Draft Mental Incapacity Bill in so far as it could affect the care given to the dying and could be used to bring human lives to a premature end, empowering or enforcing medical attendants to abstain from giving that care to which all dying people are entitled. Moreover the Bill is dangerous in the extreme, in so far as the law affects attitudes, because if it becomes law respect for human life will further diminish, doctors attending patients who have made living wills will on occasions be hampered for doing what they know to be in the best interests of the patient.

HISTORICAL

2. It is important to bear in mind some devastating events which have occurred in the last century and the beginning of this century in the hope that they may not continue or be repeated.

3. During the past century and the beginning of this century lives both of the born and unborn have been needlessly taken; killing has been legalised, witness the epidemic of abortions—about six million abortions performed since the abortion act in 1968. Doctors in the Netherlands, where euthanasia has become commonplace, have co-operated in the suicides of people with early-stage HIV, anorexia and depression. A number of doctors in the Netherlands admit to killing patients without obtaining prior consent. In the course of the euthanasia “action” programme carried out in Nazi Germany more than 80,000 mental patients had been gassed between September 1939 and August 1941¹. It is sometimes erroneously believed that the atrocities which have happened in the past cannot be repeated in this country: however all human societies and all individuals are capable of both great humanitarian acts and also evil acts mainly by doing harm to others. We must safeguard our laws and our society with the utmost vigilance not allowing any practices to be legalised which will result in harm or death to others.

CHANGE OF ATTITUDE

4. In respect of this Draft Bill certain aspects merit special consideration. First: it is of paramount importance to understand that wishes expressed by the healthy in respect of action or inaction to be adopted when they are in a terminal, critical or unhealthy condition are not usually their wishes when that condition has been reached as any member of the medical or nursing professions will attest. Attitudes change when a patient changes from a healthy individual to one who is ill. As has been stated “Euthanasia is a minority interest amongst the terminally ill.” To illustrate the point one recalls the conversation in the old persons home when it is agreed among the residents that none of them, bar one, would wish to live to the age of 100. The one who dissents is age 99.

PERSISTENT VEGETATIVE STATE

5. Hypothetical situations described to those invited to make living wills and advance decisions, which will not have to be registered and can be made orally, are fraught with dangers both for the future patients and their doctors. For instance conditions such as Persistent Vegetative State may be described to a person following which the person may be asked what would their wishes be if they became locked into this state. However the term vegetative applied to human life is inappropriate, implying as it does that the person has ceased to be a human being. Dr Keith Andrews writing in the *Journal of the Royal Society of Medicine* said “in our own unit, 40 per cent of Those with a diagnosis of vegetative state were found to be have been misdiagnosed, some for several years”.² Some patients in the supposed vegetative state have recovered—for example: a person named Patsy White Bull, an American Indian mother of four recovered after 16 years in coma in December 2000³. Medical conditions thought to be irreversible are on occasions proved to be otherwise.

¹ Second World War Martin Gilbert Chap 17 p 228.

² Vegetative State—background and ethics *J R Soc Med* 1997 90 593–596.

³ Sunday Telegraph 9 January 2000 p 24.

FOOD AND FLUID

6. While killing must always be abhorrent to a civilised society needless or burdensome treatment need not be given and should not be given to those who are dying. Nonetheless ordinary care and attention including the giving of food and fluid, on which all human life depends, must always be given. The exceptions to the rule of giving fluid is when death is imminent and the benefit of giving fluid would have no value. Death by dehydration is painful in the extreme. To see a patient who has a completely dry infected mouth and inelastic skin is to understand the intense suffering to which they are subjected.

7. It must be understood that the phrase “artificial nutrition and hydration” is a nonsense in so far as the administration of food and fluid, however administered, can never be deemed artificial or constitute medical treatment. In the same way as oxygen cannot be described as artificial if administered by a face mask. Where a patient is denied administration of food and fluid and dies of dehydration or malnutrition that patient will have been deliberately killed and will not die because of the underlying disease but of dehydration and malnutrition. The ethical principle is that nothing should be done with the deliberate intention of killing the patient.

ETHICAL PRINCIPLES

8. The commandment “you shall not kill” and the Hippocratic teaching—“I will use my power to help the sick to the best of my ability and judgement; I will abstain from harming or wronging any man by it. I will not give a fatal draught to anyone if I am asked; nor will I suggest any such thing” could be undermined if this Bill becomes law. The attending doctor could be prevented from using his/her powers to help the sick, mentally affected and the dying through a wish previously expressed either orally or in writing concerning a future hypothetical situation. This “wish” could be expressed by a third party on behalf of the patient—a situation which is open to abuse. The Bill, if adopted, would lead to the widespread practice of eugenics and euthanasia.

55. Memorandum from the Bishop of Paisley (MIB 63)

The consultation period on the Government Mental Incapacity Bill is already over one week old. As part of your consultation I would like to make the following points.

1. I really find it quite incredible that proposals for such vital and crucial decisions should be put out to a six-week consultation period in the middle of the summer holidays. I note that Parliament is itself in recess throughout this period of consultation. Once again, it appears that this Government is hoping to rush through legislation without permitting proper scrutiny and consultation.

2. This matter is so important because it touches directly on people’s human rights as well as their civil rights. The first human right is the right to life. The Bill as it has been drafted would allow Euthanasia by neglect. Such an important development in our country should be properly and adequately discussed. This is a very complex and emotive issue, which requires a full and informed discussion within Parliament and throughout the country.

I am nevertheless grateful for the opportunity given to contribute to the work of the Joint Committee and I can only hope that the members will see fit to allow an extended period of consultation in order to achieve a full and balanced consideration of the serious issues involved.

August 2003

56. Memorandum from Dr David Shakespeare (MIB 68)

I am writing to offer my comments on the Draft Mental Incapacity Bill I have five years’ experience working as a Specialist Registrar in Rehabilitation Medicine, with a special interest in care for those who have suffered severe acquired brain injury and disabling conditions such as multiple sclerosis.

Although I applaud the general intention of this Bill to clarify the Law on decision making for adults with mental incapacity, there are a number of aspects which give me grave cause for concern. I appreciate that there have been extensive discussions about this proposed legislation since the Law Commission Report in 1995, but I would urge the Joint Committee to proceed with caution as I believe that this Bill (as presently constituted) places many vulnerable people at grave risk of abuse.

A common scenario which would trigger powers authorised by this Bill (advance decisions, lasting power of attorney) would be when a person suffers a severe acquired brain injury, for example through trauma or spontaneous intracranial haemorrhage. It is notoriously difficult, even for a specialist, to give an accurate

prognosis in the early stages after such an event and decisions on commencing supportive nutrition and hydration taken at that stage may not be as fully informed as the gravity of the situation warrants. The Bill must include a stipulation that the opinion of a specialist should be sought to ascertain as accurate a prognosis as possible.

The Bill correctly states that there is a presumption against lack of capacity, but there seems to be few safeguards to support that the standard of proof is only "on the balance of probabilities" rather than "beyond reasonable doubt" (Section 3). Once a deputy has been appointed, it seems to be left up to the deputy to decide whether an incapacitated person has regained capacity for a particular matter, and no review process is specified (Section 20). This is way below the level of protection provided for persons detained under the Mental Health Act, and I would recommend that capacity should be reviewed periodically especially for those whose prognosis is not terminal (eg any non-progressive acquired brain injury). This task could be entrusted to the Medical Visitor.

It should also be made clear that it is an offence for a person to use powers contained in this Act, when a proper prognosis has not been ascertained, where there is evidence that capacity may have been regained, or where the person may be manifesting a view contrary to the previous decision. In support of this, I would recommend that an Application to the Court of Protection should be allowed by anyone who is reasonably involved in the care of someone who is alleged to lack capacity. It should also be appropriate for the Court to make an interim order prohibiting actions if there is reason to believe that the person may have capacity or may be manifesting a view contrary to the previous decision.

In the Explanatory notes (section 20 Clause 2), reference should not just be made to patients in the locked-in state, but there should also be a recommendation to seek the assistance of a Specialist Speech & Language Therapist for those with cognitive and language problems.

Finally, I remain very concerned that the measures introduced by this Bill will lead to a diminishing of the quality of care for severely disabled patients through a general feeling that withholding nutrition and hydration with the aim of ending life is in their best interests. I would urge the Committee to consider the wider effects of this Bill before proceeding to make recommendations.

July 2003

57. Memorandum from Dr Fiona Randall (MIB 74)

Thank you for your e mail of 11 August 2003 asking for some information about the expected impact of this Bill on my specific area of health care, namely palliative care.

You have asked for clarification of the benefits of the Bill. However, at the same time Susan Johnson, Head of the Mental Incapacity Division, has suggested that comments on the Bill be sent to the Scrutiny Unit at the House of Commons, and so I have sent a copy of this letter to that office, and have included in it some comments on the practical difficulties of implementing the Bill exactly as it stands.

The Association for Palliative Medicine will also be submitting written evidence on the Bill and could be asked for oral evidence if necessary, so I have copied this letter to Dr Mary Neal, current chairman of their working group on ethics, of which I am a member.

At the outset I would mention that the primary focus of the Bill appears to be on persons who have long term learning disability or chronic mental incapacity due to illnesses such as psychosis or depression or dementia. However, the Bill will clearly also apply to patients with grave physical illnesses, which, by reason of vital organ failure and consequent biochemical disturbances, will cause either confusion or impairment of consciousness. These states frequently render patients incapacitated in terms of health care decisions, either temporarily or permanently. In the context of palliative care this incapacity may be a foreseen event, but it may also be unexpected and its onset may be sudden.

My comments are based on my experiences as a consultant in palliative medicine, and also as a teacher on health care ethics to both undergraduate and postgraduate doctors and nurses, a role which I undertake partly as a result of undertaking a philosophy PhD in health care ethics. The comments below relate to the impact of the Bill on patients, their families, and health care professionals, particularly but not exclusively in the context of grave physical illnesses.

I would like to make some general positive points about the Bill initially, then proceed to more detailed comments on specific clauses.

In terms of empowerment, health care professionals already have guidance on decision-specific tests of capacity, but making the process of assessing capacity more obviously subject to clear law would be in the interests of patients and health care professionals.

The General Authority which will protect health carers provided they act reasonably and in the patients' best interests will protect patients as well, and the Court of Protection will hopefully be able to provide a timely response to resolve difficult issues and protect all parties in the process.

The Bill makes it clear that those making health care decisions for mentally incapacitated patients must make those decisions on the basis of the patient's best interests, and the emphasis on taking account of what can be ascertained of the patient's wishes will enshrine in law the guidance on consent already issued by the Department of Health. Unfortunately this guidance is not always followed, in that attention is not always given to what can be ascertained of the patient's current wishes, or of what those wishes might have been in the circumstances. By making it law to take those wishes into account, I believe that the decision making process for these patients will be improved, as health care professionals will be persuaded by the impact of the law that consideration of what can be known of those wishes is really important in these difficult circumstances. I am thinking here particularly of those cases where the professionals' natural instincts are to carry out life-prolonging measures on incapacitated patients with a poor prognosis, and they have a tendency not to pay attention to what the patient might have wanted in the circumstances. The Bill will tend to correct such partial and rather inadequate assessment of "best interests". At the same time the Bill allows life-prolonging treatment to be given pending a more considered decision, for example by the Court of Protection.

The Bill gives clearer legal force to advance refusals of treatment (although there are some practical difficulties arising from its application which I have described below).

Successful implementation of this Bill will require significant education endeavours for health care professionals and the public, and some resources will be required to enable that education to occur.

Since the process of appointing a LPA will be quite complex, will require following a strict formula, and will necessarily entail a registration process, I think it is unlikely that many patients will appoint an LPA, at least in the near future. Written advance decisions are still relatively uncommon, and they are rather easier to formulate than the LPA and do not require registration.

There are some items in the clauses of the Bill which I believe are likely to lead to difficulties in clinical practice, and in some places a very slight change in wording might help. I think there are more significant problems with the section on advance decisions. The following comments are in the order of the clauses of the Bill.

Clause 2(3) states that "all practicable steps" must be taken to help a patient decide before he is treated as unable to make a decision. This is most commendable and will improve patient care, but it will also have significant resource implications in terms of the time health care professionals, in this case fairly senior doctors and nurses, will have to commit to the assessment of capacity for these patients. There is already a significant shortage of these experienced health care staff, so time taken to implement this Bill will be at the expense of other aspects of patient care and this must be appreciated.

Adequate assessment of capacity to make decisions which are complex and require the patient to understand, retain and consider a large amount of (often distressing) information will necessarily require considerable time as well as experience and skill.

It is of course possible that as some patients will prove able to make the decision and some of them may decline treatments. If this proves to be the case then some professionals' time may be saved by not undertaking treatments which consume considerable financial and human resources but which the patient does not actually want to undergo.

Clause 4(1) states that any act done for, or any decision made on behalf of a person who lacks capacity must be made in the person's best interests. In practice this would mean that the patient lacking capacity must receive the best treatment for him/her, and must receive the care which most accords with his/her best interests. But the reality in the NHS is that treatment and personal care are effectively rationed—there are now, and will be in the future, grossly insufficient resources to give every patient what is in his/her best interests. My worry about the impact of this clause in practice is that it may force resources to be unfairly distributed to the mentally incapacitated, since by law they must have what is best for them. This would be likely to be achieved at the expense of patients with capacity who can be told the NHS does not have the human/financial resources to do what is best for them.

For example, many patients would ideally like to be cared for and die at home, providing that 24 hour care could be provided for them there by the continuous presence of a nurse. Care in the familiar environment of home might be in the best interests of the many confused or demented patients. However, such care is expensive in human and financial terms, and if it had, by law, to be made available to mentally incapacitated patients because it was in their best interests, then mentally competent patients would have to forego it to an unreasonable and unjust extent.

The solution to this problem is to include in clause 4, and subsequently in the Bill where necessary, the stipulation that the benefits of treatment and care must be distributed justly between mentally incapacitated and mentally competent patients, and the former cannot have their best interests pursued without consideration of the interests of the latter group.

Clause 4(2)(d) as written appears to give equal importance to consulting any person engaged in caring for the patient and those persons who are appointed deputies or registered as having LPA's. Surely greater legal force should be applied with regard to consulting deputies and LPA's than to consulting any person interested in the patient's welfare.

Clause 4(4) reads as though clause 4(1) re best interests will be complied with “if the person reasonably believes that what he does or decides is in the best interests of the person concerned”. Unfortunately, this implies that health care professionals need not pursue the essential steps outlined in 4(2), whereas following these steps regarding ascertainment of the patient’s wishes is really in patients’ interests and needs to be enshrined in law. Clause 4(4) would seem to provide an undesirable “let out” clause for health care professionals who for any reason do not want to consider what the patient would have wished.

Clause 7(1)(b) states that General Authority does not authorise a person to restrict P’s liberty of movement “unless there is a substantial risk of significant harm to P”. But in the context of health care it is the case that mentally incapacitated patients’ movements can cause a substantial risk of significant harm to other patients, for example by persistent wandering in in-patient units, or by causing severe noise disturbance etc. The free movement of the mentally incapacitated patients sometimes has to be restricted to protect other patients—who themselves have a right to protection from harm caused by their fellow patients. Yet General Authority in this Bill seems to prevent restriction of movement of the mentally incapacitated, which is likely to be interpreted as forbidding health care professionals from restricting the movement of such patients where it is a harm to other patients.

This problem recurs in clause 10(1)(b) and 10(2)(b) with reference to the powers of LPA’s regarding the movement of the mentally incapacitated person.

The solution is probably to include in General Authority the authorisation to restrict the movement of P where this is necessary to avert substantial risk of significant harm to P or other persons. Clearly, reasonableness as already mentioned in the clause is essential here.

Clause 7(2) would seem to mean that General Authority does not allow health care professionals to “do an act” which conflicts with a decision made by a doner of LPA or a deputy appointed for P by the Court of Protection. But if the LPA or deputy wanted a life-prolonging treatment continued for an incurable and gravely ill patient, whilst the health care team were clear that in this particular situation the harms and burdens of the treatment exceeded its benefits, then this clause would seem to prevent the health care team from acting to discontinue the treatment they felt was inappropriate. The most obvious example relates to the highly emotive issue act of switching of a ventilator. According to the Bill, because withdrawing ventilation requires professionals to “do an act” for P, then the professionals could not do this if the LPA or deputy insisted on the patient being ventilated. I suspect conflict is more likely to occur where the patient has appointed an LPA than where a deputy is involved.

This clause seems at variance with the principle that neither patients nor those acting on their behalf (eg LPA’s) can require health care professionals to provide a treatment which they believe is clinically inappropriate.

Resource issues clearly come into play here also. If an LPA could insist that a ventilator could not be switched off, then another patient who could gain benefit from that ventilator and ITU bed might be denied it, since the new law would support the LPA’s request to continue ventilation by preventing the professionals from ‘doing an act’ to patient P contrary to the LPA’s decision. The Bill might thus inadvertently force diversion of resources to incapacitated patients at the expense of those with capacity, or it might rarely impose unachievable requirements on intensive care units.

Clause 7(3) does not solve the problem illustrated in the above example.

Clause 10(4)(b) makes it clear that a LPA does not confer authority to refuse to consent to life-prolonging treatment, unless the LPA “contains express provision to that effect”. I fear this may be confusing to patients appointing a LPA for welfare decisions, who will naturally conclude that the LPA has the power to refuse life-prolonging treatment.

Clause 18(1)(h) allows “the court” to arrange the settlement of P’s property. Does this mean that the relatives of a patient, who is mentally incapacitated by reason of a terminal illness such as a brain tumour and who has not previously made a will, can expect the court to determine what should happen to the patient’s estate? Many patients are mentally incapacitated for a period just prior to death, and a significant number have not made a will. Can the court really undertake to determine what should happen to the property of this potentially large group of people?

Clause 24(2)(b) states that an advance decision is not valid if subsequent to making it the person confers authority to consent or refuse treatment on a doner of an LPA. This means that an LPA’s decision always overrides or effectively negates a prior advance decision because the latter is considered invalid. Patients would need to have a very clear understanding of this legal position, as they might (reasonably) think that their own written advance decisions should have more weight than those of a LPA subsequently appointed by them.

Clause 24(2)(c) states that “an advance decision is not valid if P has done anything else clearly inconsistent with the advance decision” previously made. This is a problem, as it is difficult to judge what is clearly inconsistent with a particular decision. The problem is important, as this clause could be used to make an advance decision invalid. For example, a patient I now know has a “Living Will” refusing life-prolonging treatment, and indeed he has refused hormone treatment for his prostate cancer. But recently he bled from a tumour in his tonsil, and then agreed to a blood transfusion. This decision seems inconsistent with his

advance refusal of life-prolonging treatment and according to the Bill would invalidate the advance decision. I think the patient would be surprised and dismayed to have his clearly thought out and recorded advance decision so easily invalidated!

In practice, patients who are competent often agree to life-prolonging treatments, for example antibiotics, whilst at the same time stipulating an advance decision to refuse life-prolonging treatment when they are mentally incapacitated. Unfortunately this Bill would mean that a decision by a competent patient to accept one life-prolonging treatment effectively invalidates an advance decision, which the patient intended to be respected when he/she became incapacitated. I think this problem needs much more consideration.

Clause 24(4)(b) and (c) make it easy for health care professionals to declare that an advance decision is not applicable. Indeed, the more specific the circumstances mentioned in the advance decision the less likely it is to apply in the exact circumstances which later arise. Unfortunately it is relatively easy for professionals (and possibly family members) to declare that some circumstances exist which the patient did not anticipate, and so to declare that the advance refusal of treatment is not applicable.

My most serious concerns about the clauses on advance refusals of treatment are that the conditions imposed for establishing validity and applicability make it rather too easy for others to declare the advance decision invalid or not applicable. Thus the patient's wishes can be rather easily overridden, albeit by well-meaning others. I think this problem needs more consideration.

Clause 28 makes it clear that the Bill does not permit anyone to make decisions regarding donating organs for transplants on behalf of an incapacitated patient. What will happen if the law changes to one of "presumed consent" to organ donation? Will no-one then be able to refuse to donate the organs on the incapacitated patient's behalf—even an LPA who knew the patient's wishes?

Clause 30(1)(a) to (e) makes it clear that much will turn on the details contained in the codes of practice the Lord Chancellor will prepare. Moreover, clause 30(6) will mean that it will be the duty of every health care professional, enshrined in law, to know about and have regard to the codes of practice. Implementing this will require resources for education of at least all trained nurses and doctors, and probably some other health care professionals as well.

I hope these detailed comments are helpful. Sometimes it is difficult to envisage what exactly will be the effects of changes in the law for patients, their families, health care professionals and the public.

August 2003

58. Memorandum from the Law Commission (MIB 203)

1. The Law Commission, which was established by Act of Parliament in 1965, is the permanent independent law reform body for England and Wales. Our main purpose is to make recommendations to Government for changing the law. About two-thirds of our reports have been implemented (wholly or in part) by legislation.

2. Publication of the draft Mental Incapacity Bill is the latest step towards legislative reform of the law on mental incapacity. In that process, the Law Commission has taken a leading role. Under the supervision of Law Commissioner Professor Brenda Hoggett, now Lady Justice Hale, the Commission published four consultation papers between 1991 and 1993, and concluded its examination of the subject with its Report on Mental Incapacity (Law Com No 231) in February 1995. That Report contained a Mental Incapacity Bill, drafted by Parliamentary Counsel.

3. The case for legislation was very strong in 1995, and remains so. Since publication of Law Com No 231, the Law Commission has pressed for governmental acceptance of the recommendations in the Report and for a Bill to be laid before Parliament. Other interested bodies, such as the Law Society and the Royal College of Psychiatrists, have added their support to the case for legislative reform. The Law Commission welcomes the fact that the Government intends Parliament to have the opportunity to legislate on Mental Incapacity and it recognises that, in most respects, the draft Mental Incapacity Bill adopts and gives effect to the recommendations of the Law Commission in Law Com No 231. Although the draft Bill might appear to be quite dissimilar from the Bill annexed to the Law Commission Report, on close analysis much of the difference is attributable to the nuances of Parliamentary draftsmanship. There are however some important substantive differences which we should draw to the attention of the Committee.

- (a) The most significant omission from the draft Bill concerns the recommendations we made in Law Com No 231 (Part IX) for the protection of vulnerable people at risk. We proposed a wide definition of "vulnerable person" to include any person (aged 16 or over) who is or may be in need of community care services by reason of mental or other disability, age or illness and who is or may be unable to take care of himself or herself, or unable to protect himself or herself against significant harm or serious exploitation. We recommended that, where local authorities have reason to believe that a vulnerable person in their area is suffering or is likely to suffer significant harm or serious exploitation, they should be under a statutory duty to investigate and to provide

or arrange community care services or to take other action to protect that person. We argued that in order to discharge this duty effectively, the authority required powers of entry, and the court should be empowered to make assessment orders and temporary protection orders. Criminal liability could be incurred by those obstructing the local authority in the exercise of these powers or any person acting pursuant to an assessment order or temporary protection order. We also recommended that local authorities should have powers to assist a vulnerable person in bringing proceedings for an order under the private law (such as a non-molestation order or an ouster order) and to take reasonable steps for the protection of the property and affairs of a person who is without capacity to protect them and for whom they provide or arrange accommodation.

- (b) Part IX was integral to our recommendations and we regret its omission from the draft Bill. Our consultees had supported the reform of public intervention on the ground that the existing law was “ineffective in protecting elderly, disabled and other vulnerable people from abuse and neglect, and inadequate in its approach to issues of autonomy and individual rights.” (Law Com No 231, para 9.1).
- (c) The draft Bill confers “general authority” on a person providing care for another who lacks capacity to do an act which it is in all the circumstances reasonable to do. The restrictions placed on that general authority are narrower than those recommended by the Commission in Law Com No 231. Part VI of that Report stated the case for independent supervision of certain serious medical interventions (sterilisation, tissue or bone marrow donation, abortion, treatments for mental disorder, withdrawal of artificial nutrition and hydration, non-therapeutic research procedures) which we believe should require, depending on the type of intervention, court approval and/or an independent second opinion or some other kind of supervisory mechanism. These recommendations are not given effect to in the draft Bill.
- (d) Our recommendations concerning advance decisions to refuse treatment are largely carried forward. The draft Bill does not however give effect to our recommendation, based on public policy grounds, that an advance refusal should not preclude the provision of “basic care” to maintain bodily cleanliness, to alleviate severe pain and to provide direct oral nutrition and hydration (Law Com No 231, para 5.34). But it may be that the general law already recognises this.
- (e) The draft Bill does not appear to make adequate provision for access to the health records of the person who lacks capacity. It is important to provide for such access to allow the deputy to make informed decisions as to treatment and health care (Law Com No 231, para 8.23).

4. We recognise that most of these changes are the result of earlier Government consultations. The Commission hopes that legislation dealing with Mental Incapacity will shortly be enacted. In view of the time, which has elapsed since publication of Law Com No 231, there is little that the Commission itself can currently offer by way of assistance to the Committee, as none of the Commissioners, or legal staff, involved in the Mental Incapacity project remain at the Commission. We do however understand that Lady Justice Hale, as the former Commissioner in charge of the project, would be happy to offer the Committee examining the Bill such assistance as she can provide and we will give her such support as we can. She can be contacted at the Royal Courts of Justice, Strand, London WC2A 2LL or by email at bhale@lix.compulink.co.uk.

August 2003

59. Memorandum from Professor David d'Avray (MIB 204)

My mother was in a coma for six years. After her death I corresponded and talked with Mr M I Hinchliffe of the Official Solicitors office about such situations. I feel I know something about them and hope you will take it into account.

My mother was not in a vegetative state but she was paralysed and it was unclear how much she understood. Her first consultant (Dr Simpson of Chichester Hospital) did not think it good that she should survive, and refused to treat an infection. (She survived anyway.) However he agreed with the family that nourishment should not be withdrawn. He said that he thought it would cause distress. You need to think through the implications.

Mr Hinchliffe's view was that patients in a permanent vegetative state suffered not pain, but he added: “I acknowledge that the same may not be the case in relation to patients whose condition falls even slightly short of this.” (Letter dated 18 December, 1996). He is a man of integrity whose opinion should carry much weight with you.

Note that neither Dr Simpson nor Mr Hinchliffe shared my own feeling that it is wrong to intend a patient's death even through inaction. They nevertheless did not deceive themselves about the possibility of distress caused by withdrawing nourishment from patients not in pvs.

When beds are short in hospitals or when places in a kindly nursing home have financial implications for families there is a danger of doctors and family members assuming too easily that a patient is in pvs: It would be naive to assume that such self-deception is impossible. Even without it mistakes could be made.

Mr Hinchliffe (tremendously honest and fair despite our disagreements) told me of a case in his personal experience that you should find worrying. Before the coma the person had indicated that they did not wish to be kept alive in circumstances such as actually transpired: a light coma allowing for minimal communication through signals. Mr Hinchliffe visited this patient in his professional capacity and was able to ask what he or she wanted (I forget if it was a man or a woman but he would certainly remember). He told me that he was rather shaken when the patient clearly indicated a wish to be kept alive. This makes me think that living wills are dangerous.

I suppose that patients in pvs do not suffer when kept alive: what of the others? Having spent so much time with my mother over those six years I can say that quality of life is possible. Her family were able to show her constant affection, she watched tv, the staff of her nursing home treated her as a person. She was aware, followed one with her eyes etc, and my father told me that a day or two before her death she spoke. I suppose her quality of life was much better than that of a severe depressive. There is a lot that can be done with perfumes, ointments, videos etc to make it bearable. You have to have had such a situation in the family to realise how different the whole thing is from situations you see on tv.

Later one of my acquaintances told me that he had himself been in a coma for a short period after an operation that went wrong. He understood everything that was said around him but had no sense of time. I could put you in touch with him if you wish (he lives in Germany).

As you can see from the above, the proposed Bill fills me with disquiet.

August 2003

60. Memorandum from James and Catherine Reid (MIB 206)

We would like to make the following points as regards the Draft Mental Incapacity Bill.

1. New Clause—we urge the committee to add a new clause which outlaws the withdrawal of food and fluid in order to cause death.
2. “Patient’s best interests”—this requires a clearer and more precise definition. Chance remarks overheard or the perception of someone’s wants, wishes are too vague. It would preserve the human dignity and rights of all concerned if “objective medical criteria” could be written into the Bill. These should include—restoring and maintaining health of patient but where no cure is possible an insistence on control of symptoms including pain.
3. Lasting Powers of attorney—the right of patients to name proxies in the event of their becoming mentally incapacitated should be included in the Bill. In this way the reasonable will of the patient can be respected and family members so named are able to represent the patient and enter into dialogue with the medical staff.
4. Appeal system—to counterbalance any person nominated as proxy who acts out of self interest rather than in the best interest of the patient, doctors should be protected by being able to appeal. Similarly families and patients would be protected also.
5. Advance Directives “Living Wills”—we urge that the House of Lords Select Committee finding that advance directives are helpful to doctors and carers in decision making but warned against making them legally binding in Statute Law be applied to this Bill. There is the danger that patients can be depriving themselves of treatment discovered after they have signed an advanced directive. We urge the Standing Committee to NOT make Advanced Directives legally binding in Statute Law.

August 2003

61. Memorandum submitted by Alan W Briglin (MIB 231)

As the father of a severely handicapped son, I am writing to give my support to the Mental Incapacity Bill which is before a Parliamentary Scrutiny Committee at present, and hope it will be passed forthwith.

20 August 2003

62. Multiple submissions—Example 1 (MIB 403)

I would like to record my concern that the “Draft Mental Incapacity Bill” will erode further the human rights of the most vulnerable people in our society. The giving of food and water to any patient is not a treatment but is a basic right that ought to be available to all. The withdrawal of food and liquids is in fact the starving to death of an innocent person, this is euthanasia. I request that the heart of this Bill should be the best clinical interest of the patient. There should be no cases of assumed wishes or feelings, of either patient or relative at the expense of the patient’s best interests—ie their health.

August 2003

63. Multiple submissions—Example 2 (MIB 411)

I have grave concerns regarding the Draft Mental Incapacity Bill, which is currently being debated by Parliament.

Whilst it is always sensible to make every effort to plan ahead, especially for a time when our health or faculties may begin to fail, we should be able to do so without fear that someone else may deem it preferable to have our life terminated.

I am particularly concerned that this Bill would enable people who want to “plan ahead for possible incapacity” to give a carer, relative or friend the authority (a “Lasting Power of Attorney”) to deal with decision making on their behalf on financial, welfare and healthcare matters. There have been cases in the past when such a trust on matters of finance have been violated for financial gain. Such a violation is serious, but in matters of life and death this would be even more serious.

Accepting that an individual may order the termination of another’s life because they can truthfully or even falsely claim to have heard them express a wish to be dead is horrendous. Most people will at some time or other experience occasions when life appears to be a burden. Thankfully most people live through such experiences and find that life really is worthwhile after all. Even patients with a terminal illness can, with the aid of modern drugs, be assisted to live the final part of their life as comfortably as possible and with dignity. The withdrawal of food and fluids is to deprive them of their right to do so. To expect doctors, nurses, relatives or carers to assist in the termination of a life is to deprive them of the right to obey their conscience.

Because a person may appear to us to be mentally incapacitated does not mean that they are incapable of enjoying life in their own way.

As a civilised nation our aim should be to make adequate provision for the care of our less fortunate incapacitated members.

None of us knows what fate may have in store for us. But we should all be able to feel reassured that no matter what happens to us we will be allowed to live out our lives with dignity, surrounded by love and provided with every medical means to ensure us comfort and ease, without the fear that our life will be forcibly taken from us.

August 2003

64. Multiple submissions—Example 3 (MIB 429)

I wish to protest about the proposed legislation (above). I am a great admirer of the Hospice movement, which enables the sick to die with dignity. Why take away from those working in these caring institutions their loving and caring vocation?

This is murder, asking medical people who took up their profession to care for the sick and infirm to terminate their existence. If the intention is to end life then there are more humane means of committing murder than denying the sick food and drink.

This government has stated that it is completely opposed to euthanasia, how then can this Bill become law?

August 2003

65. Multiple submissions—Example 4 (MIB 110)

As asked

The Society for the Protection of the Unborn Child has asked for a Response to the Governments proposed draft mental Incapacity Bill.

The basic facts against as I see it, are:

- (1) Feeding by Tube has been re-defined as Medical Treatment, but this basic humane action is not a medical decision. Denying food can be terminating life even if the illness is not terminal.
- (2) Advance decision taking is not seen as only for the terminally ill but for just on the grounds of mental incapacity. Advance refusal of treatment is incompatible with the Human Rights Act.
- (3) Power of Attorney makes the decision of Euthanasia by neglect legally binding although this would be a subjective and not a medical decision.
- (4) In Living Wills, legislation should exclude termination of life.
- (5) Doctors or Care staff should not be fined or punished for attempting to give food, or drink to their charges. This degrades the moral character of both the doctor and the patient. It would pervert the purpose of medicine which is to save life.
- (6) Any law which legalises euthanasia by neglect would send a signal to society that the lives of the mentally incapacitated are not worth living. Is the Ethos and Ethics of our society, the survival of the fittest?

To take life is a perversion of medicine. First do no harm.

I would like these considerations to be considered and the bill to be amended bearing these in mind.

August 2003

66. Memorandum from Ms Teresa Lynch (MIB 409)

1. The government gives repeated assurances that it is opposed to euthanasia. However, euthanasia does and has included withholding or withdrawing tube-feeding with the intention of bringing about the patient's death since the early 1990s in this country. In addition, the Voluntary Euthanasia Society, whose aim is to establish the right to kill and be killed, has assisted the Government in its documentation relating to decisions required for treatment or lack of treatment for those patients who may or may not be at the end of life.

2. "Competence" is a dangerous word to employ in these situations. No right thinking individual would readily agree to death by starvation and dehydration. Proper informed consent is doubtful in situations where lay people are to be involved in such momentous decisions over life and death. It is surely not humane to put either "competent" or "incompetent" patients through such avoidable stress, where reasonable means can be employed to ensure best clinical care.

3. The British and European courts overwhelmingly rejected the concept of a "right to die" in the Dianne Pretty case. Patients in a vulnerable state will perhaps feel that euthanasia is the best option open to them, in particular, disabled people.

4. Financial expediency is never the answer to a "problem" of a vulnerable individual or any group considered to be economically or physically "non-viable". The increasingly-used term "bed-blockers" will become prime candidates for the abandonment of care.

5. Patient quality of life should not be considered on physical condition alone. Dignity, like autonomy, can only be generated by trusting relationships. The right to good clinical care is a paramount right of any patient, and the first responsibility of any individual, worthy of the name of Doctor, Nurse or Parliamentarian.

6. Lastly, in my professional opinion, the foreseeable implications of such a Bill are profound in relation to future motivation, recruitment and retention of both nurses and doctors. To my certain knowledge, the sinister encroachment of bad guidance on the duty of care is causing attrition rates in both professions, so long dedicated to the well-being of patients. Such a Bill if passed, in current form, will reflect both a total lack of compassion for people in need and respect for professional vocation, training and expertise.

I hope these points may assist you in your deliberations.

Draft Mental Incapacity Bill submission: The Rights of nurses who may encounter distressing clinical directives in the work place

The labour of nursing is acknowledged as comprising both physical and emotional elements to be part of their work. Recent national and professional guidance may now be an unforeseen pivotal factor in the attrition rates of nurses both prior to and post the nurse registration process.

MY QUESTION IS TWO-FOLD:

1. What support will be available to nurses (and Doctors) who are unable to follow clinical directives which are incongruous with their own belief systems?
2. Nurse attrition rates: a frequent result of unresolved stress when attempting to work with repeated ethical conflict in the clinical area?

BACKGROUND

Considerable changes in the training and expectation of nurses have occurred over time. These were designed, in part to manage the reduction in junior doctor hours, and would herald a new view of nursing among co-professionals.

The climate in nursing in the UK is one of a developing autonomy with nurses taking on an increasing number of these expected developed roles. Progress is ongoing on the plan for nurses to be able to prescribe a more comprehensive range of medications than the current limited amount agreed by the Medical profession. Nurses are now able to be Consultant Nurse Specialists, Physician/Surgeon assistants and even take on the role of Endoscopist. To some extent these changes have increased the acceptance of nursing as a profession on a par with other University-based, professional training programmes. Closer links have evolved between the medical and nursing professions. Nurses are expected to take on the roles formerly within the province of junior medical staff. The profession of nursing is now linked increasingly to the responsibilities of Medicine.

This technical aspect of the nurse's role expansion and the professional recognition has not always equated with the expected recognition in other more expressive areas of nurses' work which also involves close association in medical decision-making. Medical staff can now dictate a decision for withdrawing or withholding life-prolonging medical treatment (British Medical Association 1999). Such situations can distress many nurses, whose long-held wish, in most cases, would be to maintain their caring skills to meet the needs of their patients for both physical and psychological well-being.

THE CONCEPT OF CARE

Care is perhaps the most basic element of a patient's treatment that a nurse can provide, yet it is the most essential.

The term "Care" is derived from the Anglo-Saxon "to trouble oneself". This impulse, together with the desire for nurses to put the interests of others' good before their own, can be a clear declaration of a nurse's own ethical position.

"The Essence of Care" Department of Health initiative was developed with the active participation of patients and their carers as well as hundreds of health professionals. It offers a practical toolkit to be used as a part of quality improvement programmes. It will also become an integral part of clinical governance at local level.

The eight areas addressed by "The Essence of Care" document are: privacy and dignity; nutrition; principles of self-care and record keeping; personal and oral hygiene; continence and bladder and bowel care; pressure ulcers; and the safety of clients with mental health needs. They are all seen as fundamental to achieving the basics of care. The "Essence of Care" defines patient-focussed best practice and then sets out the steps necessary to achieve the benchmark. Staff can use the pack to work with multi-disciplinary colleagues and patient representatives to consider how well they are performing in structuring the sharing of good practice within comparison groups and across an organisation. The clear role of nurses who wish to care for patients in line with such ideals can conflict with the professional views of others in certain clinical situations.

THE NURSE AS ADVOCATE

A form for such caring impulses can be seen in the role of the nurse as Advocate. This role has been described as one of the most difficult a nurse has to face. Advocacy has been described as "not a slogan or a hobby, nor to be entered into by the faint-hearted" (Copp 1984). The advocate role, though not only expected of the nurse within the multidisciplinary team, can often be an inevitable result of the twenty four-hour responsibility of nurses for patient care.

Patients' own Care plans were generated with the aim of giving individual patient care, and have been part of the nurse's care orientation and training for over thirty years in this country as in America.

There are various reasons for the nurse finding difficulty in the role of advocate. Despite good approaches that have developed in multidisciplinary team work (particularly in the field of Gerontology). The Doctor is often the ultimate arbiter of any treatment plan.

CO-PROFESSIONAL GUIDANCE

Recent Medical guidance has abrogated one of the historical functions of the nurse. Helping patients with their nutritional needs, whether involving assisted food and fluids, has always been an expected part of the total nursing care of patients.

The original BMA guidance and the following guidance of the General Medical Council (2002), in relation to assisted food and fluid as "treatment" is opposed by many nurses, but application of such guidance, may become the norm in practice.

The guidance from the BMA, was the result, in part of the notable case law in relation to the young man, Tony Bland, who was suffering from what is described as a "persistent vegetative state". This case elicited from one of the lawyers at the time, a warning that nurses involved in this case would have to cope with being expected to go against all their training preparation, but would need to realise that the agreed course of action, (discontinuation of the feeding programme), would be in the best interest of all concerned.

PROFESSIONAL CODE OF CONDUCT FOR NURSES

Nurses are bound by their professional Code of Conduct. Their unchanging professional expectation is the clear duty of care, to safeguard the public and at all times to put their patients' interests and safety first (NMC 2002).

Despite this Code, some nurses are placed in positions of conflict by the demands of other professionals, managers and contexts of employment which may clearly compromise their duty of care. Such situations can induce considerable stress for the nurse, who attempts to act as patient advocate and not least when threats of disciplinary action or suggestions that they are not coping, are employed against them.

THE ELDERLY

The National Framework for older people aims, among others, to make treatment decisions on the basis of clinical need, not age. The overall aim backed by £1.4 billion (invested every year by 2004) is better health and social care services for older people (DOH 2002). This move may prove beneficial to those who are supported at home by the Government's community care aims for older people. The number of people over 90 years of age will double in the next 25 years. There are examples of poor, unresponsive and insensitive treatment and sometimes, simply because of the age of patients. Denying access to services on the basis of age alone is not acceptable. The Government's drive to raise standards of care, particularly those relating to patient empowerment, is not restricted to the NHS and extends to the independent sector. The consultation document "For the Future" (DoH, 1999) epitomised the Government's commitment to establishing required standards for residential and nursing homes in recognition of the somewhat sketchy regulations set out in the Registered Homes Act (DoH, 1984).

Another source of conflict (and confusion) for nurses, results when worthwhile initiatives, propelled by national directives can be seen to contradict other, more questionable directives.

GOVERNMENT PLANS

The Government, in October 1999, published its proposals to reform the law on mental incapacity, which have now been enshrined in its draft Mental Incapacity Bill (2002).

By April 2002, draft "guidance" was issued by the Government on management of people unable to make decisions about their own treatment and care. The Government claim that it does not wish to introduce active euthanasia but is silent about euthanasia by neglect. It is moving ahead with plans that would introduce the routine denial of assisted nutrition and hydration, which could be labelled as passive euthanasia.

This Bill applies to any adult who is mentally-incapacitated and will therefore affect every single person in this country, because everyone is vulnerable to accidents or illnesses that may cause mental incapacity. The Bill's radical proposals include using a system of living wills and unqualified, unaccountable attorneys to force doctors to withdrawing life-sustaining treatment and care (commonly understood to include also assisted food and fluid). If passed, the Bill will be the first comprehensive law in the world allowing euthanasia by neglect and may become a model for all common-law countries.

This new draft guidance has been launched with the aid of the Voluntary Euthanasia Society and the clear aim is to allow the starvation and dehydration of incapacitated people. The guidance also recommends the use of the “living will” drawn up by the VES. No mention is made, however, of the known pitfalls of “Living Wills” or “Advanced Statement Refusals”.

This guidance will affect people able to feed themselves but who need considerable basic medical and nursing care, (eg elderly and or disabled people). In many cases these people will not die but become chronically-sick “bed-blockers” with little prospect of alternative accommodation in light of the many nursing home closures in recent years.

The Mental Incapacity Bill could lead to a possible situation where one statement which request or agrees to a refusal of treatment would be all that is required to end that patient’s life once the stage of mental incapacity is reached. For a doctor to continue to administer treatment (including assisted food and fluid) would be illegal.

The nurse who cannot agree with some of the planned changes, and certain defeatist approaches to those most vulnerable, may feel compelled to leave his or her chosen profession. This may become the only possible course of action, if unsupported in the view that the duty of care should not be ignored devalued or interpreted with malice.

Professionals, relatives and employers may argue that the expedient action or omission of care, which they may believe to be “in the best interests” of the patient, is also in line with a human right to “die with dignity”.

The nurse, who believes that human dignity is not contingent on physical condition but inherent to the individual, and like autonomy, is dependent on trusting relationships, may only experience the vision of patients in need, being abandoned by their carers.

Nurses and Doctors also have human rights. The professions need to examine what impact on their mentors (and patients in turn), will result if these rights to practise within a vocational, caring perspective are denied.

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August 2003

67. Memorandum from Miss Lucy A Underwood (MIB 451)

1. The Draft Mental Incapacity Bill is a far-reaching piece of legislation, affecting every person in the United Kingdom since every person is vulnerable to accident or illness which could cause mental incapacity. The range of situations the Bill covers is potentially very wide, and the assumptions and attitudes inherent in its proposals open the door to an entirely new, and dangerous, way of looking at end-of-life care and incapacitated/disabled people. Given these considerations, the time allowed for the consultation process by the Joint Committee has been disproportionately short and does not, I think, give concerned individuals (which means every person in this country) sufficient opportunity to voice their concerns.

2. The concerns raised by the bill are several, among the more serious of which are: the possibility of abuse of the system of “Lasting Powers of Attorney”; the inclusion of food and fluids under the definition of “medical treatment”; and the assumptions apparently being made concerning the value of human life in the definition of “best interests” of the patient.

3. The possibilities of abuse of extending the existing “Enduring Powers of Attorney” system to include healthcare are illustrated by the case of Mrs Marjorie Niglibert, Florida, USA, who had given Lasting Powers of Attorney to her brother, who ordered her feeding tube to be removed; a court decided Mrs Niglibert was not mentally competent to revoke the LPA, and so she was effectively starved and dehydrated to death, although conscious and heard to ask a nurse for food. The LPA system could be open to abuse since the person with LPA would in many cases be a relative or other person likely to benefit from the patient’s will, and ulterior motives in ordering a patient’s treatment to be stopped could well come into play in certain cases.

4. Another concern is the coercion of doctors that such a system would cause. A person not necessarily with legal or medical qualification could order doctors, effectively, to kill a patient. This goes against the inherent purpose of the medical profession—to preserve life, promote health and alleviate suffering—and would mean overriding any moral or religious objections to such practices which a doctor or nurse might have, the Draft Mental Incapacity Bill makes possible a situation in which a doctor could be punished for treating his patient—or even simply feeding his patient—against the wishes of an unaccountable relative or acquaintance with Lasting Powers of Attorney.

5. UK court precedent has established that artificial nutrition and hydration is to be classified as medical treatment, and thus under the Draft Mental Incapacity Bill it could be withdrawn. This is, frankly, inaccurate. Food and fluid, however administered, are basic care such as any human has a right to; they are not extraordinary treatment. This principle, taken to its logical conclusion, implies that if I were to stab another person with a knife, or inject them with a lethal poison, I would be guilty of murder; but if I merely locked them in a room without food or water and left them there until they died, I would simply be allowing nature to take its course. This would not be a defence any court of law would take seriously—unless the victim of my actions were unable to swallow, the food were being given them through a tube, the room was a hospital ward and I had Lasting Powers of Attorney.

6. In addition, death by starvation and dehydration is extremely painful, even to a person deemed “incapacitated”. The case of Marcia Gray (Rhode Island, USA) illustrates this harrowingly: she had been comatose for a year in 1987; she and her family had expressed a wish that extraordinary measures not be taken to extend her life; as a result, a Court ordered her feeding tube to be removed. It took some time to find a hospital willing to take this patient for the sole purpose of starving her to death; when she was transferred and her feeding tube removed, she took 15 days to die, during which time she lost 50 pounds in weight, and physicians had to sedate her heavily to control her violent seizures. It may well be but a short step from there to giving a lethal dose to a patient in whom “nature” seems to be taking a rather long and agonising course.

7. It is an evasion of the issue for the Government to state that it is opposed to euthanasia, since it defines euthanasia as a “deliberate intervention undertaken with the express intention of ending a life”. But a deliberate omission with the same intention and the same effect differs only in method; on any honest assessment, euthanasia by omission is also euthanasia. The only time at which it is appropriate to withdraw or withhold basic treatment or food and fluids is when death is immanent—that is, the person is dying—not just likely to die in the fairly near future—and no benefit can be derived from the intake of food and fluids (however administered) or basic treatment.

8. The proposed system of Advance Directives, enforced by second persons with Lasting Powers of Attorney, raises serious concerns about how disabled (including mentally incapacitated) people are viewed by the legislators of this country. Doctors, instead of acting according to the person’s clinical “best interests” (ie preserving the patient’s life and health and alleviating their suffering), are required to act on the person’s “wishes and feelings” as expressed perhaps years before, in a different situation to that the patient is now in, and quite possibly when treatments available at the time of illness were not available. Even further, the “advance statement” according to the Bill need not be written but can be made orally. Thus, in basic reality, all that is legally necessary to starve a person to death after, for example, a severe stroke, is for a person to state to the Court of Protection “Mrs X said three years ago she would not want to be treated if she were in this condition”—and any doctor or other person who tries to prevent Mrs X from being starved and dehydrated to death will be liable to prosecution. This is not protection.

9. However, while the inclusion of oral statements as Advance Directives is of particular concern, Advance Directives in themselves are inadvisable, since, as suggested above, they rely on subjective, past “wishes and feelings”. To be killed is never in a person’s best interests, although in a state of fear, depression or pressure (real or perceived) from family/acquaintances a person may lose the will to live; such patients require good, respectful palliative care, not an affirmation by law and society that they are worthless. It is not possible for another person to judge someone else’s life worthless because their medical condition looks, to us, disturbing and pitiable and because it may be irremediable.

10. By allowing that any lives are not worth living, we are opening the door to a mindset in which any disabled person is a mere “burden”. As in the Netherlands, where both active and passive euthanasia are legal, we may reach a situation in which the elderly are afraid to go into hospital in case the doctors kill them, and where people carry cards requesting that they not be killed, by act or omission, in case of illness—in the hope that this may prevent doctors from carrying out acts of involuntary euthanasia. This may seem a long way from the proposals of the Draft Mental Incapacity Bill; but every thousand-mile journey starts with one step, and it is essential that we look at the long-term effects of this proposed legislation in terms of society’s attitudes and ideology.

August 2003

68. Memorandum from the Salford Diocesan Fellowship for the Handicapped (MIB 457)

I write on behalf of the Salford Diocesan Fellowship for the Handicapped with comments on some aspects of the Draft Bill being considered by your committee. The Fellowship has many members with learning disabilities, some of whom are profoundly disabled. We have a particular interest in any legislation, which could affect their rights.

1. We firstly express concern that so little time has been granted for written submissions to be made, particularly over the busy holiday season, when it is not easy for organisations to collect the views of members.

2. Many of our members do not have the “capacity” to make decisions about their own care. We believe strongly that they have the same right to life and preservation of life as any other human being and view with dismay proposals in the Bill, which could make them even more vulnerable to the misguided decisions of others.

3. Whilst we support totally the view that people should be allowed to die with dignity, we are strongly opposed to the proposal that the withdrawal of food and fluids is in the best interests of people. Planned death by dehydration of terminally ill, elderly and incapacitated people is completely unacceptable. We do not believe that this is in anybody’s “best interests”. The medical profession is still not able to judge the degree of suffering endured by mentally impaired or unresponsive people from whom fluids are withdrawn. Far from improving an individuals comfort, it contributes to the suffering.

4. This Bill will in effect create the climate that euthanasia by neglect or omission is lawful. This devalues human life. It is only a step away from deciding that the life of any person who is mentally impaired can be terminated.

August 2003

69. Memorandum from the Islamic Medical Association UK (MIB 469)

I am writing to you to express my deep concern and objection to the new Mental Incapacity Bill in context of the potential of withdrawal of food, fluids and necessary treatment to terminally ill/mentally incapacitated patients.

Islam like other monotheistic faiths upholds the sanctity and sacredness of life, so much so that an analogy of any individual terminating an individual’s life is given in the Quran (chapter 5: verse 32); it is likened to the “slaying of the whole of mankind and on the contrary anyone saving a life, it is as if he has saved the life of all of mankind”.

We have a responsibility and a duty to protect the most vulnerable in society as healthcare professionals and to place a clear and defining line between treating and harming our patients. One area where this can truly be exemplified is in the last hours, days or months of any terminally ill/mentally-incapacitated individual. Why deny their basic human rights; to the simplicities in life such as food and drink, when they are at their most vulnerable, possibly unaware or unconscious.

Many individuals cite “to die with dignity” is a basic human right and I would agree, to die with dignity means as medical healthcare professionals to provide necessary nutrients, fluids, medicines, analgesia and counselling/company to make an individual comfortable during their remaining years.

The introduction of any legislation allowing the withdrawal of food/fluid from any patient or to neglect life saving treatment is euthanasia by omission and a crime against the sanctity of life. The potential for abuse of this type of legislation by all members of society for personal, social or political gain is too of grave concern. This has only been recently emphasised—by the “Shipman” enquiry where advantage of the more vulnerable groups of society lead sadly to numerous deaths over five decades.

Hence, I urge you on behalf of the members of the Islamic Medical Association (IIMA) to reject the introduction of the Mental Incapacity Bill and return basic human rights to all in society at a time where each and every one of us will be at our most vulnerable.

August 2003

70. Memorandum from the Labour Life Group (MIB 601)

We in the Labour Life Group have a number of concerns about the Draft Mental Incapacity Bill in its present form:

1. A clause should be added to the Bill outlawing the withdrawal of nutrition or hydration with the intention of causing death. The provision of nutrition and hydration cannot be classified as medical treatment, even if it is by a tube.

If I discovered you tied up and I neither untied you so that you could get your own food and drink nor gave you food and drink, I would be responsible for your resulting death as surely as the person who tied you up in the first place.

I am not suggesting that nutrition and hydration should not be withdrawn if it is causing distress to the patient, because then it would be being done to relieve the patient's suffering. If the patient's condition was such that the patient's body was unable to gain sustenance from the nutrition and hydration provided, then it would be appropriate to withdraw nutrition and hydration in this case also.

But, apart from these two tightly defined areas, nutrition and hydration should never be withdrawn. I know that for me to differentiate between the provision of nutrition and hydration via a tube and some other forms of care, which I would define as medical treatment, may seem to some people to be a very fine distinction, but I feel that it defends a principle and that principle protects vulnerable people. As a disabled person, myself, I think that makes it a very important distinction.

2. There needs to be a clearer definition of a patient's best interests. The Draft Bill defines these vaguely as the patient's wishes or what someone else imagines their wishes to be. The Draft Bill is so vague it could mean a chance remark the patient once made while watching television.

The Bill should be amended so that a patient's best interests involve objective medical criteria including the restoration and maintenance of health. Where no cure is possible, best interests must include control of the symptoms, including pain.

3. Where patients are not competent, proxies legally entitled to act for the patient should be allowed to make decisions on the acceptance or refusal of treatment, as envisaged in the Draft Bill. However, there must be safeguards to ensure that proxies are acting with due respect for the patient's reasonable will and legitimate interests and are not motivated by self-interest.

4. There needs to be a system of appeal to protect the rights of doctors, those with powers of attorney, or family and friends.

5. While the House of Lords Select Committee welcomed advance directives as being very helpful to doctors and carers, it warned of the dangers of making them legally binding. One reason they gave was that patients could deprive themselves of treatment developed after they signed the advance directive. Advance directives should not be made legally binding in statute law. The Government claims that advance directives are already legally binding in case law. However, I would challenge this opinion on the grounds that there has been no definitive case.

6. An ORB survey on euthanasia and assisted suicide found that doctors are extremely concerned about the possible effects of advance directives. Only 40 per cent said that they would follow an advance directive if the patient was unable to confirm it, while 49 per cent said they would seek the advice of a colleague. Six per cent said they would refuse to follow the directive, while 3 per cent said they would withdraw from the case. Actually, 71 per cent said there were circumstances in which they would ignore advance directives. The reasons they gave were the same sort of concerns expressed by the Select Committee.

I hope our concerns will be addressed in the next draft of the Bill.

August 2003

71. Memorandum from Mr John Mandry, Support Worker, SHOUT (MIB 689)

I am writing on behalf of the committee and membership of SHOUT to raise our grave concerns about the above mentioned Bill, specifically Clauses 6 and 7. As they stand these appear to have little or no safeguards for people with learning disabilities.

Clause 6 appears to start from nowhere, via somewhere and back to nowhere. It seems to be a somewhat insubstantial format given the consequences of the definition of incapacity. Surely some form of formal assessment should be made that is accountable in law, preferably by a panel or something akin? These should also review the incapacity at regular intervals. I would also hope that the person judged to be incapable would have recourse to appeal against decisions. This does not appear to be part of the Bill. If it is, then this is well hidden.

Clause 7 subsection 1, which has an even more tenuous hold on reality, is also a really big worry. If there are not built-in safeguards or a code of practice like the one for the 1983 Mental Health Act (Clause 19) then it leaves much scope for abuse of all kinds.

We fear that the above clauses, either separately or in concert will by accident or design end up denying people with learning difficulties real life choices. Given the paucity of resources generally available it could be a distinct possibility.

As it is, we feel that people will suffer due to the somewhat simplistic view when applied to people with learning disabilities and feel that any legislation which affects them should be done as distinct law, rather than jumbled in as at present.

August 2003

72. Memorandum from Self Advocacy in Action (MIB 690)

We are a group of people with learning difficulties from North West Leicestershire and South Derbyshire, and have been meeting together since 1987.

We have looked at the guide and would like to make the following comments.

On page 3 point 2 we think you should also mention different ways of communicating with a person when you are helping them to make a decision for themselves. This is talked about on page 4 point 4, 30 this point really should come after point 2 page 3.

On page 5 point 1 you mention "there will be a list of things to think about." This list is also referenced on page 6, page 8 point 4 and page 9 point 2. It would be helpful to know what's on the list, then we could decide if the Bill was any good or not.

On page 8 point 2 the wording of this paragraph is confusing and makes it difficult to understand.

On pages 8 and 9 you describe Lasting Powers of Attorney and a Court Appointed Deputy. What are the criteria for deciding who can make a decision to have a LPA and who has to have a Court Appointed Deputy?

On page 10 point 3 would the person be able to go back on an advance decision and say I do want to have the treatment? Could you tell us what the "strict rules" are?

On page 11 point 2 you say that there will be "special judges and staff". Could you tell us what extra training they would have for this? We suggest that people with learning difficulties should train them.

On page 12 you talk about the "public guardian". How many public guardians will there be and what would be the size of the area that they cover?

On page 13 you talk about the new law. We would like to know about the other things the new law will cover.

Finally the draft Bill doesn't mention a person's right to have an independent advocate.

We hope that you take our views into consideration.

August 2003

73. Memorandum from the All Wales User Survivor Network (MIB 711)

1. The All Wales User and Survivor Network is Wales' largest independent user-led organisation for mental health service users. With approximately 600 members across Wales, the US Network aims to provide an effective voice for users and ex-users of the mental health system. Therefore the Network is ideally placed to respond to the draft Mental Incapacity Bill as it affects those who experience mental health difficulties.

2. In view of the piecemeal nature of previous legislation the new Act is timely in its attempt to provide a more systematic and coherent approach for those experiencing mental incapacity.

3. We particularly welcome the fact that the Bill does not attempt to label individuals as "incapable", but rather seeks to establish capacity for individual decisions on a case-by-case basis. We think it appropriate that the Bill assumes that all adults have the capacity to make their own decisions unless it is proven that they do not.

4. As regards the Lasting Power of Attorney we agree that a service user should be able to nominate a person or persons who will be able to make decisions on their behalf as regards financial, health and social care matters.

5. As regards Advance Directives we agree that these, when made by a service user when they have capacity, should be adhered to when they are deemed to have lost capacity. In order to be meaningful we believe that these, when made in the proper manner, should be legally binding and therefore enforceable.

6. We do have concerns, however, that in practice, Advance Directives may be ignored when enforced treatment is administered under the Mental Health Act.

7. We therefore request that greater clarification is provided in the Act and Explanatory notes about how Advance Directives are expected to work in conjunction with the Mental Health Act.

8. In particular, we would suggest that it is recommended that all professionals who are considering enforcing treatment under the terms of the Mental Health Act verify with the user and/or their carer at the outset whether they have made an Advance Directive.

August 2003

74. Memorandum from Rev Dr Francis Marsden (MIB 713)

May I establish my own interest in the draft Bill in question? For 19 years, I have been a priest of the Catholic Church. For seven of those years I was chaplain to either a large general hospital (Walton Liverpool) with busy A&E and neurological departments, or to geriatric hospitals in Chorley, Lancashire. In my current parish, we have two nursing/residential homes for the elderly and I occasionally take the hospital bleep to substitute for the duty chaplain. All my priestly life I have regularly visited the sick and the elderly parishioners in their homes with Holy Communion.

On a personal level, moreover, my mother is now 85 and has problems with arthritis, a faulty heart valve, blood clotting and glaucoma. I have delegated Power of Attorney for her, should she ever become incapable I also exercised Power of Attorney for my mother's cousin, my godmother. For several years until her death in 1996, I administered her affairs when she was incapable with Parkinson's Disease and in a residential home.

I also lecture at Maryvale Institute Birmingham (distance learning) on a Medical Ethics Module for their MA in Personal, Spiritual and Moral Development.

The aspect of the Mental Incapacity Bill which concerns me is in particular the section on Advance Directives. Previously the Government had said that it did not intend to legislate on "living wills." I wish therefore to comment upon Paras 23–25 of the draft Bill.

There are several problems with such advance directives.

The state of mind of a person in good health is not necessarily that of a person when they are ill several years later. A person's decisions and thoughts may change radically when they are seriously ill. The patient may then find himself at the mercy of a written document made a long time ago, which no longer expresses his/her intentions, and yet be incapable of signifying his/her altered wishes. Even if he or she does make some indication that he wants a particular treatment, if he/she is deemed not to have the mental capacity to express his or her wishes, then that indication is likely to be ignored. Such a document may then come to express the dictatorship of the past over the present.

The draft Bill does not appear to stipulate that an Advance Decision to refuse treatment must have been properly drafted, written down and witnessed. "Word of mouth" reports, where someone with Lasting Power of Attorney merely says that "P said to me she didn't want to be resuscitated in the event of X" or "P didn't want to be treated in the event of Y" are surely inadequate and open to gross abuses. Large sums of money and property are sometimes in the balance when a person nears death, and sad to say, it is hardly unknown for certain relatives to have a vested interest in death occurring sooner rather than later. The very sick and the dying need much better protection than this Bill affords.

The House of Lords Select Committee, which reported in 1994, opposed giving advance decisions greater legal force, saying this would risk “depriving patients of the benefit of the doctor’s professional expertise and of new treatment and procedures which may have become available since the Advance Directive was signed.”

Secondly, I note that the sections 23–25 cover only “Advance decisions to refuse treatment.” Surely, this should be widened to include Advance decisions to stipulate certain sorts of treatment, when these are medically feasible.

There has been considerable concern ever since the Bland judgement, which in my opinion mistakenly reclassified artificial nutrition and hydration (food and water delivered by nasogastric or intravenous tubes) as medical treatment rather than a basic human right. This opened the way for artificial feeding to be withdrawn if it was deemed “inappropriate.” However, food and water is a basic human right which I would maintain can never morally be “withdrawn.” We must do all we can to make sure a patient receives nutrition until it becomes practically impossible, and the person is dying anyway from other causes. Certainly, the starving to death of patients eg stroke victims, who are not terminally ill, but seriously incapacitated, is a form of passive euthanasia morally equivalent to homicide. Such euthanasia by omission is contrary to the fundamental principle of medical ethics: *primum non nocere*—first, do no harm.

The possibility, even the remote possibility, that a relative with Power of Attorney might be able to give legally binding instructions to medical staff (who could be prosecuted for disobeying) that a sick relative is to be deprived of hydration and nutrition, and condemned to a slow and painful death by starvation and thirst, is abhorrent.

Euthanasia includes not merely active lethal measures to procure the speedy death of a patient, but also the deliberate omission of available medical care, in order to hasten their demise. Disthanasia, the undue and burdensome prolongation of life to no purpose, is also wrong. There does come a time to let nature take its course: I have on several occasions been with families in the intensive care ward when the time came for a respirator to be turned off, because a severely brain damaged patient had no chance of recovery whatsoever and was by all accounts already brain dead. It was my role to commend the dying person’s soul to Almighty God. However, it is not the role of the doctor or medical staff to hasten a seriously ill or dying person on their way.

As a priest, I consider that the last days of a person’s life on this earth are of immense spiritual importance. It is a time for the dying individual to make their peace with God, and with their family and relatives, if they need to. As a person approaches death, and I have seen this many times, it is as if the veil of transcendence grows very thin, and for all concerned it can be a most moving and valuable experience of spiritual reality. It may also be an area of experience in which decisions about advance directives made long ago in robust health, now have little value given the new realities of the situation.

If the Government is sincere in its stated opposition to euthanasia, and wishes to advance the true best interests of people who are mentally incapacitated, it should make it clear that whatever a person may have (allegedly?) stated in an advance decision, there can be no obligation on doctors to carry out unethical acts such as depriving a person of food or fluids or appropriate treatment. Incapacitated people, like all human beings, are entitled to the best available treatment, given in their clinical best interests.

It is a valuable safeguard that the Mental Incapacity Bill provides for punishment if a person “ill treats or wilfully neglects” a mentally incapacitated person in his or her care. However, in permitting the withholding or withdrawal of food and fluids, with the purpose of ending life, the Bill itself sanctions such “wilful neglect” by starving and dehydrating a vulnerable person to death.

Section 4 of the draft MIB also lacks clarity, insofar as it attempts to define a patient’s “best interests” without clear reference to their health and best clinical interests. Are not “Past and present wishes and feelings” rather too nebulous without some clearer legal mechanism for ascertaining precisely how those wishes are to be expressed and evaluated? What about people who are severely depressed or suicidal? Would medical staff have to go along with their wishes and make no attempt to bring them out of a clinical depression? Are there times when the impartial but concerned and experienced observer does know better than the individual himself or herself what is good for them? The policeman who goes up onto the roof of a block of flats to talk a suicidal man into coming down is, in a way, being paternalistic.

Unlimited autonomy would suggest that we just leave the man to kill himself if he so wishes, and make no attempt to dissuade him for fear of infringing his “autonomy.” Unlimited autonomy can be hard to live with. There are times when we are victims of our own mood swings and emotional state, and need the reassurance and guidance of others.

Moreover, there needs to be some over-riding statement about the preservation of life, health and consciousness wherever possible, along with adequate pain control treatment. This encompasses the basic role of the medical profession, but it appears to be lacking in the draft.

I hope that necessary amendments can be made which will cover these points, which I am sure many other people have also made.

August 2003

75. Memorandum from Dr Gillian Craig (MIB 726)

Clause 4. Best Interests

The criteria used to consider “best interest” are far too vague. Lord Brandon’s “principle of necessity” has proved its worth and should not be lightly discarded. A treatment should be considered “necessary” “if, but only if, it is carried out to save their lives, or to ensure improvement or prevent deterioration in their physical or mental well-being.” [Reference Re F(1990)2ACI]

The principle of necessity has proved valuable to doctors faced with the management of patients with mental incapacity, for example those with severe dementia or strokes, who are unable to give informed consent about necessary care. It was also used to good effect by a Judge in Australia who intervened to save the life of a 37 year old man, who languished untreated and in danger of death in a hospital in Sydney. (Northridge v Central Sydney Area Health Service [2000] NSWSC 1241 (29 December 2000))

Parliament should not ignore the views of the House of Lord’s Select Committee on Medical Ethics of 1994. They considered that life-prolonging fluids and nutrition should not be withheld unless the means of administration is evidently burdensome to the patient. Yet in hospitals all over the UK elderly patients are having such measures withheld. It is in no one’s best interest to be starved to death.

Case Report

Mrs X was an elderly lady who had suffered a stroke. She was admitted to hospital semi-conscious. Within days of admission a “not for resuscitation order” was issued against the wishes of her son. She was given subcutaneous fluids for some days. On the 12th day a nasogastric tube was passed, through which she was given virtually nothing but tap-water until she died, grossly emaciated, seven and a half weeks after admission. This calculated negligence was considered to be in her best interest!

Clause 6. General Authority

(3a) This should be altered to permit a person “to reimburse himself out of money in P’s possession, *with the approval of a relative or other responsible person.*” (Unless the words in italics are added, a person could incur expenditure and help themselves to an incapacitated person’s money without so much as a “by your leave.”)

Clause 7(2)

This clause should be clarified to make provision for appeal to the Court of Protection in the event of any serious dispute about decisions made by the persons mentioned in 2a, and 2b. Therefore I suggest that you add a third point 2c as follows—

(c) In the event of serious concern about decisions made in sections (a) or (b) above, a ruling should be sought from a court.

Clause 16(4a and b)

I note that the proposed Court of Protection will operate on the understanding that a decision by the Court is preferable to the appointment of a deputy, and that the powers of any such deputy “should be as limited in scope and duration as possible.” This surely throws into question the whole issue of proxy-decision makers! Yet under the terms of the draft Bill, it is proposed to permit members of the public to appoint deputies (ie proxy decision-makers) with power to make crucial life and death decisions on their behalf. This makes little sense!

Clause 17(1d)

The wording should be clarified. Does “a treatment” include “life-prolonging/life-saving treatment” (as specified in clause 10 (4 a and b))?

Clause 24. Validity and Application of Advance Decisions

Section 2 invites chaos and muddle! How can the Government possibly argue that advance decisions are legally binding and must be heeded when there are so many situations that undermine their validity? Advance directives should be taken as indicators of a patient's wishes, not as hard and fast rules. They should not be enshrined in statute law.

Busy medical practitioners simply do not have the time to consider the legal validity of an advance directive, and may not know of its existence, when faced with urgent life and death situations. Many such crises have to be dealt with in the absence of any information about the patient. (For further discussion see Craig GM. *Catholic Medical Quarterly* of Feb 1999.)

I suggest that the point made in clause 25(5) should also appear as clause 24(5).

Clause 30. Codes of Practice Powers of the Lord Chancellor

The Bill as drafted gives far too great power to the Lord Chancellor. He/she is to be allowed to revise codes of practice as thought fit. If changes are made at frequent intervals it will be extremely difficult for people to comply with a duty [see clause 30 (6)] to have regard for "any relevant code of practice" It is hard enough for professionals to keep pace with all the codes of practice and guidelines in circulation, some of which appear to contravene the European Convention on Human Rights. It will be impossible for ordinary members of the public to be aware of relevant codes of practice. This is yet another reason for suggesting that the final word on life and death decisions should not be given to unqualified proxy decision-makers. Such people should be involved in an advisory capacity only; good practice should ensure that their views are heard in consultation with those of others in the caring team.

Clause 40. Application to the Court of Protection

(1) Access is too restricted. Any person should be permitted to apply to the Court of Protection on behalf of an adult with mental incapacity, just as any person can refer a case to the Coroner. In the USA and Australia, necessary court cases have arisen when relatives disagree with decisions made proxy health care decision-makers—for example a spouse acting as the legal guardian. Where a person has no close relatives, a concerned friend or professional should be allowed to apply to the Court for advice.

A new clause should be added to permit application to the Court of Protection by any concerned health care professional, relative, close friend or other significant party who disagrees with decisions made about P by significant others.

Clause 41. Court of Protection Rules

The element of secrecy (41:2g) is potentially sinister. Some record should be kept of all "end-of-life" decisions made by the Court, whether or not there is a hearing. The statistics should be made public. Without this we will never know how many applications (and people) are "disposed of" with or without a hearing. [see 41; (2e)]

Clause 43. Rights of Appeal

The public need to be assured that there will be a right to appeal to the Court of Appeal without undue restriction. There should be a Right of Appeal to the Court in any situation where a person's life is put in danger by decisions made by health care professionals or proxy decision-makers. There will inevitably be some conflict between such parties in the years ahead. The Court should be the final arbiter.

August 2003

76. Memorandum from Dr David Kingsley (MIB 731)

I am responding to the inquiry into the proposed Mental Incapacity Bill in my capacity as a practising clinician and also as a doctor with an interest in Medical Ethics. I hold specialist registration in Psychiatry with the General Medical Council. Over the years I have worked in a number of clinical disciplines, my experience of which leads me to have some grave concerns about the Bill in its current form, which I will detail below.

1. INTRODUCTION

1.1 The need to provide improved decision-making structures and protection for those who lack the capacity to make decisions for themselves cannot be questioned. However, I believe that the proposals within this Draft Bill would do the opposite, in a similar way to proposals in the previous 1997 Green Paper “Who Decides”, as I pointed out at the time (Kingsley 1999). The current proposals would disempower vulnerable people and make them prone to decisions being made on their behalf that they may neither agree with nor would be in their objective interests. Such decisions may include decisions about their very life or death. Furthermore, clinicians may actually be forced to act against their judgement of a patient’s best interests, in such a way as to cause the patient to be seriously harmed or killed. As such, this Bill would be more likely to do harm than good to vulnerable adults, and should have no place on the statute book of a democratic country that claims to wish to support and protect its vulnerable citizens.

2. BEST INTERESTS

2.1 *The “New” Medical Ethics*

2.1.1 It has been traditionally held in routine medical practice, as expressed in the Hippocratic Oath, that a doctor should always attempt to act in a patient’s best interests. The Oath states, “I will follow that system of regimen which, according to my ability and judgement, I consider for the benefit of my patients, and abstain from whatever is deleterious and mischievous. I will give no deadly medicine to any one if asked, nor suggest any such counsel; and in like manner I will not give to a woman a pessary to produce abortion.” Such an interest in doing what is “for the benefit of my patients” particularly applies to the treatment of those who are incapable of giving consent or of expressing their personal wishes in regard to the treatment they may receive. However, over recent times, a shift in ethical values within medicine and society has led to this principle being over-ridden. The most clear example of this is in regard to the acceptance of the practice of abortion within medical practice. This undermined the entire ethical basis of medicine up to this point. The maxim *primum non nocere* or “first do no harm” has been abandoned. Obstetricians who previously considered the lives of both of their patients equally (the unborn child and its mother) now willingly slay one patient (the incapable silent one) at the whim of the other. Human persons are now created for the prime purpose of experimentation and then murdered in embryological research. Embryos are discarded every day in IVF procedures as they are “not needed”.

2.1.2 In order to justify such practices, Medical Ethics have moved from absolutist positions such as that expressed in the Hippocratic Oath, where life is considered to be a basic good due to all, to more relativist utilitarian positions. It is now felt that not only the best interests of the patient should be considered, but the interests of society, relatives, doctors and other staff, society, finance, etc. One can easily see how such a shift leads to decisions being made that are clearly NOT in the patient’s best interests.

2.1.3 I believe that it is essential in this Bill to re-think the definition of “best interests”. It is, of course, helpful to take into account the person’s past and present wishes and feelings as well as those of their relatives or representatives. But these considerations should never override certain objective ethical principles as well as a clinician’s judgement about the best assessment or treatment options available. Also, I strongly believe that it is never in a patient’s best interests to be subject to any act or omission that has the direct intention of causing their death. This particularly applies (as I will mention below) to the withdrawal or withholding of food and fluid from a patient, which I believe is always unacceptable.

2.1.4 The relevance of this massive shift in medical practice now influences many areas of clinical practice. For example, those with Learning Disability are often treated with disdain and receive poor medical care. I have personally had to fight for medical care for such people, when clinicians from other specialities have not seen their lives as of enough value to be worth treating with the same standard of care as their other patients. Moreover, people with Learning Disabilities are particularly vulnerable to being physically or sexually abused by others. It is now common practice for a person with Learning Disability who lacks the capacity to enter a sexual relationship, to be allowed to be sexually exploited by other patients (who may also have limited capacity). This is seen to be giving them their “rights”—but is actually allowing them to be abused. The only issue that is considered is to ensure that the patient is sterile—either by using injectable contraceptives or enforced sterilisation “in the patient’s best interests”. In my mind this is legally sanctioned sexual abuse, but it is now considered routine practice. I am somewhat encouraged to see in the Bill (Section 1, Para 26) that it is not considered possible to make a decision on behalf of an incapacitated person in regard to them having sexual relations. I hope that this will bring to an end the widespread practice I have mentioned of allowing people who do not have the capacity to make such decisions to be preyed upon sexually.

2.1.5 Lord Mustill, a member of the 1993–94 House of Lords Committee on Medical Ethics and a member of the appellate committee that decided the case of Airedale NHS Trust versus Bland (1993) went so far as to suggest that Tony Bland, who was in a Persistent Vegetative State, had NO best interests because of the nature of his disability. This is a shocking statement and shows how far Medical Ethics have deteriorated to this point. PVS is a condition where much of the cerebral cortex is not functioning, but the brainstem, which controls basic functions of life, works fine—the patient’s heart beats and lungs breathe quite normally. All that is required is that the patient be fed—no different from a newborn baby. And yet

a senior Law Lord can say that such a person has NO rights. But then neither does a newborn baby up to the very minute of its birth in current legislation, so it is not hard to see how such a judgement could be made in the current climate. I have had to witness the delivery of a dead full-term baby whose mother had taken a train to London the day before for the baby to have potassium solution injected into its heart to kill it. The baby had some late-identified imperfection that led its mother to decide she would rather it died than lived. I find such practice sickening—it appears to me to have more in common with Nazi Germany than with a so-called democratic society that claims to wish to protect its citizens. I find it ironic in the extreme that we make such a fuss about the case of Harold Shipman, when I have colleagues who are mass murderers of unborn children and are sanctioned in their actions by government. It does not make me very proud to be a doctor.

2.2 *Food and Fluid is Basic Care, not Medical Treatment*

2.2.1 Along with the change in ethical values, has come a change of language and meaning, in order to allow for practices to take place that would otherwise be inconceivable. A key manipulation of language took place within the Bland case, in regard to redefining food from basic care to medical treatment. In my view, this was an appalling decision, that gives doctors the power to choose who lives and who dies—because none of us, whether ill or not, will survive long if we are not fed or watered. I believe that there is a duty of care to ensure the provision of such care to all patients, irrespective of their mental capacity or physical condition. If it is not possible to provide nutrition and hydration by ordinary means, a doctor still has a duty to find a way of doing so even if a “medical procedure”, such as the insertion of a PEG tube, is the only possible method. If a patient has the capacity to consent, then the initiation and ongoing use of artificial feeding requires consent, as would the “natural” feeding of a patient with a spoon or cup, if this were required. If a patient with the mental capacity to do so decided to refuse such care, it would constitute suicide; if the decision were made for him it would be murder. In the case of a patient without the capacity to consent, all should receive food and fluid, by whatever means are necessary as part of the basic care due to them.

2.2.2 Obviously, if a patient is in the actual process of dying, the insertion or use of a tube during these hours may be intrusive and inappropriate. However, this could not be used as a valid reason for withholding food or fluids if the time taken to die was so long as to put the patient at risk of dehydration or starvation and the consequent suffering.

2.2.3 I would argue that there is no ethical difference between “withholding” and “withdrawal” and would therefore state that there are no moral grounds for either withholding or withdrawing food or fluid, whatever means may be necessary to administer this care.

2.2.4 Many people are dependent on artificial hydration and nutrition who are in little or no imminent danger of death from their medical condition. Patients in PVS fall into this category. I entirely reject the judgement in the Bland case, which I would maintain was not about “withdrawal of treatment” but about killing a man by omission of the food and fluid he needed to survive, leading to a barbaric death from dehydration and starvation. By omitting to feed a newborn baby one could kill it in a similar way, as it is completely dependent for its survival, and yet this would be considered infanticide. There is no philosophical difference between the two cases; only a difference in the language used which makes the first instance seem to be a compassionate treatment decision and the second, clearly murder.

2.2.5 The fact that the withdrawal of food and fluid leads to such a slow and unpleasant death by dehydration and starvation, would appear to be, perversely, one of the reasons for the “pro-death” euthanasia lobby being so supportive of such withdrawals of food and fluids. The reason for this may be that they may then hold up such cases of unpleasant deaths as increased reason for legalising the possibility of putting these unfortunate people to death “humanely”, by a “quick and painless” lethal injection. We must fight the possibility of this progression by strongly rejecting the necessity for any patient to die in this inhumane way, by having their basic human right to food and fluid withheld or withdrawn.

2.2.6 In actual fact, the withholding or withdrawal of food and fluids sanctioned by the Law Lords in the Bland judgement already constitutes euthanasia, as defined as “the intentional killing by act or omission of a person whose life is felt not to be worth living”.

2.2.7 Many Health Professionals share this assertion that food and fluid should not be considered as medical treatment. Following the Bland judgement, the Royal College of Nursing (1993) said: “The RCN view differs from the judgement of the Law Lords in that nurses believe that to stop food and drink is a different issue from the decision to stop other forms of medical intervention”. I believe that any planned legislation needs to reverse previous statements and clearly state the difference between food and fluid and other medical interventions, namely that food and fluid constitutes basic care. Statute law needs to overturn the Bland judgement in order that euthanasia by omission is once more outlawed in our country. Otherwise the outlook for the weakest and voiceless in our society can only get worse rather than better.

2.2.8 The Human Rights Act (1998) also seriously contradicts the Bland judgement, and would be in opposition to the Mental Incapacity Act were it to come into force. Article 2 clearly asserts each human person's right to life and Article 3 protects against degrading or inhuman treatment. I find it hard to see how enshrining in law the right of doctors to starve patients to death (who otherwise would not be in a life-threatening condition) can be countenanced in the light of this Act.

2.2.8 In summary, I believe that for the Mental Incapacity Act to provide any sure protection to vulnerable people, it is essential that the Act overturns recent case law by defining the provision (by whatever means are necessary) of food and fluid as basic care, not medical treatment, the withdrawal of which can never be justified, unless the person is close to the point of death and would not suffer the consequences of dehydration or starvation.

2.3 *Importance of Accurate Diagnosis and Prognosis*

2.3.1 It is essential that patients in whom the withdrawal of treatment is being considered, have their diagnosis confirmed and a firm prognosis made. Where there is doubt regarding diagnosis or prognosis, as is often the case, no decision to withdraw or withhold treatment should be made. There will otherwise inevitably be patients who have the potential for recovery who do not receive the medical treatment they deserve.

2.3.2 This issue applies particularly in regard to Persistent Vegetative State (PVS), which may be misdiagnosed, and the prognosis of which may be poorly judged. In all cases regular specialist assessment by Rehabilitation Neurologists and Neuropsychologists should take place to make a firm diagnosis and assess the possibility of specific functioning linked to tiny amounts of functioning cortex. These patients should not be treated in a District General Hospital, or even many Rehabilitation Units, as they should be placed in a unit where the timeframe can accommodate for the slow pace of recovery. In the Royal Hospital for Neurodisability in Putney, such a specialist unit, an element of recovery has been seen up to two and a half years after the onset of PVS and many have recovered up to a year after onset. As there is a 95 per cent five-year mortality for PVS, those not destined to recover will die a natural death soon enough. I repeat that it is never appropriate to kill these patients by withholding or withdrawing their food and drink, however administered, as this can never constitute medical treatment. It would, however, be reasonable after all hope of recovery had passed, to withhold aggressive treatment of intercurrent illnesses allowing a natural death to take place. It would be important for the Medical Visitors appointed by the Court of Protection to include specialists in Rehabilitation Neurology, in order that vulnerable patients (especially those suspected of being in PVS) are guaranteed adequate assessment and treatment, rather than inadequate management and premature death—as is often the case currently.

2.3.3 It is important to stress that there are, of course, circumstances in which it is not appropriate officiously to strive to prolong life. Initially a full assessment of the patient, including second opinions where necessary, should take place in order to confirm the diagnosis, prognosis and possible treatment options. Where there are doubts regarding these elements, active treatment should not be withdrawn. Treatment should only ever be withdrawn inasmuch as it allows a patient who has a serious and irreversible condition to die a natural death. Palliative Care principles should guide such treatment as may be necessary to allow death to be as comfortable as is possible, without intentionally shortening life. Food and fluid should never be considered as medical treatment in this circumstance.

3. ADVANCE DIRECTIVES AND STATEMENTS AND TREATMENT DECISIONS

3.1 *Impossible to obtain truly informed consent*

3.1.1 I reject that Advance Directives have any moral or legal validity, irrespective of their content. Legislating for their use would be dangerous and would significantly reduce the protection offered to the most vulnerable. Valid consent or refusal to treatment is only possible when the patient has full knowledge of the condition from which he is suffering and the exact treatment being offered for this condition. Neither of these criteria can be fully met in an advance directive, therefore the documents can never be valid.

3.1.2 I would go further and suggest that it is also essential for a patient to actually experience a situation to know how they feel about it and hence how they wish to be treated. It has been convincingly shown that the "well" choose differently from the "sick". Gardner *et al.* (1985) studied high tetraplegics who had been kept alive by artificial ventilation and found that of 21 asked, 18 would have chosen to be electively ventilated again, should the need arise. Two more were undecided. This response differs markedly from that which one would expect from the general population who might imagine themselves being in such a situation. Therefore, even if it were possible to provide the information required for informed consent in advance of the circumstances, it would still be impossible to consider such an advance decision as valid.

3.2 *Clinical Implications of Advance Directives*

3.2.1 Even if a patient could (theoretically) validly refuse or consent to treatment in advance, there are further ramifications of advance directives. A doctor then has to act upon the directive, which may not be compatible with his ethical values or clinical judgement. His autonomy is thereby excluded entirely. He should not be bound to act entirely in accordance with this directive in spite of his own moral reservations or clinical opinion of the patient's "best interests" or prognosis at that time. At the very least, it is imperative that a conscience clause similar to that within the Abortion Act is added, in order that doctors who do not find it acceptable to kill patients by withdrawing their food and fluid may be able to opt out.

3.2.2 The content of Advance Directives is also often faulty, with vague statements about the nature of conditions in which a patient may find themselves and the treatment they would want to receive or not receive. A typical form of words in Advance Directives refers to a medical state "which is likely to be irreversible". However, medical prognosis is somewhat on a par with weather forecasting in Britain—frequently right, but often hopelessly wrong. Many patients may end up not being treated for perfectly treatable conditions simply because they had unadvisedly signed an Advance Directive, leaving the clinician powerless to stop the patient dying a quite needless and/or unpleasant death. Vere (1984) summarises it well by suggesting that "A living will says, in effect, to a doctor: 'If you could know what you don't know, then I would like you to act as I believe you would were you to know it'".

3.2.3 Medical science advances at an ever-increasing pace. New assessments and treatments become available all the time. However, if a patient has made a previous Advance Directive, they would be unable to revoke this (if they lack capacity) in order to receive a new treatment. The House of Lords select committee that reported in 1994 acknowledged this issue, saying that giving Advance Directives legal force would risk "depriving patients of the benefit of the doctor's professional expertise and of new treatments and procedures which may have become available since the Advance Directive was signed."

3.3 *Advance Decisions and Mental Illness*

3.3.1 As a psychiatrist, I feel that one key issue is the distinction between a wish to die and a suicidal intention in the context of a mental illness. I am not sure that the distinction can be made. This has serious implications. Patients who are suffering from a severe mental illness (and hence lack the capacity to make the decision to die) may be given state sanction to kill themselves. Were this to be the case, they would be seriously let down by the health system that should be able to protect them from themselves until they are so recovered as to lose their suicidal intent.

3.3.2 However, it is important to be aware that this issue does not simply relate to a small group of patients with primary psychiatric illness. Kathol and Wenzel (1992) found that among 128 patients admitted to a general medicine ward, one third of patients had major depression. This is not surprising—being physically unwell and in pain or discomfort can be a depressing experience for many people. Many such people may feel that life is not worth living any more. They may express such views openly. However, it is important to realise that such people may well be suffering from a Depressive Disorder that leads them to feel this way. What they need is treatment for their mental disorder in addition to their physical illness—not the offer of an Advance Directive that encourages their morbid wishes to be put into practice. It is likely that in most such cases, the patient's "suicidal" wishes will change following successful treatment.

3.4 *Summary*

3.4.1 For the above reasons, I feel that it is essential that Advance Directives do not become legally binding upon doctors. I accept that a verbal or written statement of future wishes regarding treatment may be helpful in informing a doctor prior to a relevant treatment decision, as may the views of close relatives or friends of the patient. But the doctor must be able to make a final decision, made primarily in the patient's best interests, which incorporates his own view of the current clinical condition, the prognosis and the available treatment options. I would hence suggest that the Bill clearly rejects the legal validity of any Advance Directive.

4. LASTING POWERS OF ATTORNEY AND THE COURT OF PROTECTION

4.1 *Lasting Power of Attorney*

4.1.1 This power is currently a useful instrument to enable a trusted person, usually a relative, or occasionally a solicitor, to manage someone's day-to-day affairs when they become incapacitated, often due to a chronic illness such as Dementia. However, the proposal to extend such powers to health decisions changes the nature of the instrument entirely. To literally hand the power for a person's life or death to a relative (who may stand to gain considerably financially by the patient's demise) is a preposterous suggestion. A case of such a situation was that of Marjorie Nightbert in the US, in a nursing home after a stroke. The Court judged her "not mentally competent" to revoke the power of attorney given to her son, despite her having being heard to ask a nurse for something to eat. She was hence deprived of food and fluid leading to her death on April 6 1995.

4.2 *The Court of Protection*

4.2.1 Similar to the situation with Lasting Power of Attorney, the Court of Protection currently has jurisdiction only in regard to financial decisions. It is planned in this legislation to transfer the current High Court jurisdiction over disputed decisions in healthcare cases to the Court of Protection. It is surely ironic that a so-called “Court of Protection” would potentially have as one of its central roles the condemnation to death of vulnerable patients by the withdrawal of their fluid and nutrition. Would judges who were opposed to medical murder in this way be given the option to withdraw from such a role?

5. ECONOMIC AND EUGENIC CONSIDERATIONS

5.1 *Economic Issues*

5.1.1 As I have mentioned, in contemporary medical ethics it is deemed necessary to consider not only the benefits and harms to the patient, but also those to others—including society as a whole. Western democracies are currently facing an impending economic crisis due to the aging population. Birth rates have steadily dropped over recent decades, to the point where the number of births has dropped below the necessary replacement level of 2.1 births per woman. The European Union as a whole has a 1.4 child per woman birth rate. In the UK the rate is 1.75. Alongside this, the number of people surviving to old age increases all the time. The economic burden to care for an ever-increasing number of elderly people is falling on ever fewer people of working age. Essentially, if western society is to avoid implosion and economic collapse over the next half century, there are two options. Either young people need to begin having more children, or the elderly need to be drastically reduced in number. I would argue that the former of these suggestions is the only serious potential solution—but unfortunately my view is not shared by contemporary society, where there is little sign that people are prepared to choose to welcome children into their families in greater numbers. Such factors as transient itinerant relationships, ever-increasing divorce rates and career-obsessed women fuel this situation. On the other hand, the possibility that significant numbers of older and handicapped people with chronic and expensive to treat illnesses could be removed from society could be seen as economically appealing by some. A bill such as the proposed Mental Incapacity Bill would do just this. It does not seem, then, too far fetched to suppose that one of the aims of this Bill might be to save the state money by killing many of its most chronic and expensive patients.

5.2 *Eugenic Issues*

5.2.1 “Eugenics” is a term coined by Francis Galton, an English psychologist and half-cousin of Charles Darwin, late in the last century. He explained the term as the principle of encouraging better human stock to breed and discouraging the reproduction of less desirable stock, thereby improving the human race. This expanded Darwin’s theory of natural selection into a concept of deliberate social intervention, which he held to be the logical application of evolution to the human race. Gobineau subsequently wrote that a fair-haired Arian race was the best human stock from which to breed. Shortly after this, these ideas were expanded further by a British-born German citizen named Houston Chamberlain, who upheld the German race to be the purest form of Arianism and regarded Jews and Afro-Caribbean people as inferior races. At the same time, eminent psychiatrists, aware of the heritability of many mental illnesses and the difficulties in treating them, turned to eugenics as a means of eliminating mental illnesses if they couldn’t be cured. From this idea came the mental hygiene movement, founded amongst others by Sir Cyril Burt, who also founded MENSAs, the high IQ group which also espouses eugenic principles. Prevention of the birth of the mentally ill was the prime aim. Laws began to be passed, including the UK Mental Deficiency Act of 1913, which segregated the mentally ill from the rest of the population. Other laws were planned for the sterilisation of the insane. The rise of the Nazi party in Germany allowed the mental hygiene movement a free hand. In 1931 the eugenicists hoodwinked the German public by campaigning for voluntary sterilisation. Within four months after the Nazis came to power in July 1933, a law allowing compulsory sterilisation of all suffering from hereditary disease was passed. But the eugenicists had more in mind. They flooded Germany and England with propaganda campaigning for voluntary euthanasia. In 1938 Professor Werne Catel, a professor of Neurology and Psychiatry at the University of Leipzig, persuaded Hitler to authorise compulsory euthanasia in 1939 for inmates of Germany’s mental institutions. 275,000 were killed. It wasn’t until 1941 that the policy was also extended to Jews and other undesirables.

5.2.2 After the war, the name of eugenics was so heavily associated with the Nazis that a whitewashing procedure began. Eugenicists began to infiltrate organisations as fifth columnists and set up ostensibly unrelated institutions. Among these institutions were the Voluntary Euthanasia Society, the Marie Stopes Memorial Foundation, the Family Planning Associations and the International Planned Parenthood Foundation. All of these organisations were supported by the Eugenics Society. It is time that we recognised that eugenics has made its comeback in the form of the abortion and family planning lobby, the euthanasia pressure groups as well as the current obsession with human genetics and weeding out the so-called “abnormal”.

5.2.3 More unborn children have died since the introduction of legal abortion than were ever killed by the Nazis. As I have mentioned it is now legal in Britain to murder a child up to the day of its birth if it is deemed to be less than perfect. We create human persons to experiment upon and then kill. We create

embryos in order to choose the best ones to implant for IVF treatments and then we discard the rest. We now are prepared to starve vulnerable patients to death by denying them the food and water that all of us depend upon for our existence.

5.2.4 My grandparents died in Bergen-Belsen concentration camp in 1945. My medical colleagues (eminent psychiatrists in particular) were the first to collaborate in the Nazi holocaust. In memory of my grandparents and in reparation for the disreputable history of my profession, I am not prepared to stand idly by and accept the current revival of eugenic killing that is taking over the practice of medicine in Britain. This Bill is a thinly veiled means of establishing in legal statute the extermination of the most vulnerable and least “valuable” members of our society. It cannot be left unopposed by those who value each human person, from their conception to their natural death, as having equal worth and dignity.

6. SUMMARY OF MAJOR POINTS IN THIS SUBMISSION

6.1. The contemporary medical ethic has abandoned the Hippocratic tradition of medicine, where life was valued as an absolute good, and where any act or omission where the intention is to end life would be unacceptable. This is the moral context into which this Bill is inserted.

6.2 The concept of “best interests” needs to be based on a sound medical ethic. Some objective principles need to be applied. It can never be in a patient’s best interests to be killed by act or omission, especially by dehydration or starvation—a particularly unpleasant manner of death.

6.3 Vulnerable patients need to be properly protected against acts against them that are not in their interests—such as the widespread practice of allowing learning disabled patients who lack capacity, to be preyed upon sexually, often by other patients. This abuse is compounded by enforced sterilisation or injectable contraception, which is also administered without consent.

6.4 All patients, regardless of their disability, need to be considered as human persons of equal value and dignity. Lord Mustill’s disgraceful statement in the Bland case that Anthony Bland had no best interests was tantamount to saying that he was not human. Such a eugenic attitude has no place in law-making in a democratic country. This Bill needs to counter such bigotry by offering true protection to all vulnerable people, no matter the level of their disabilities.

6.5 For the Mental Incapacity Act to provide any sure protection to vulnerable people, it is essential that the Act overturns recent case law by defining the provision (by whatever means are necessary) of food and fluid as basic care, not medical treatment, the withdrawal of which can never be justified, unless the person is close to the point of death and would not suffer the consequences of dehydration or starvation.

6.6 The Human Rights Act (1998) seriously contradicts the Bland judgement, and would be in opposition to the Mental Incapacity Act were it to come into force. Article 2 clearly asserts each human person’s right to life and Article 3 protects against degrading or inhuman treatment. I find it hard to see how enshrining in law the right of doctors to starve patients to death (who otherwise would not be in a life-threatening condition) can be countenanced in the light of this Act.

6.7 Advance Directives can never be valid, whatever their content, as it can never be possible for a patient to give informed consent unless they have full knowledge of the condition from which they are suffering and the exact treatment being offered for this condition. These conditions can only be adequately fulfilled at the time, not in advance. Moreover, it has been well demonstrated that the “well do not choose in the same way as the sick”.

6.8 The contents of an Advance Directive may not be compatible with a doctor’s ethical values or clinical judgment. He should not be bound to act entirely in accordance with this directive in spite of his own moral reservations or clinical opinion of the patient’s “best interests” or prognosis at that time. At the very least, a conscience clause, similar to that within the Abortion Act, should be added, in order that doctors who do not find it acceptable, for example, to kill patients by withdrawing their food and fluid, may be able to opt out.

6.9 One third of medical inpatients have been found to suffer from Major Depression in addition to their physical condition. Many patients who may express wishes to die or make other Advance Directives may not be capable of making such decisions due to their mental states. Such patients require psychiatric assessment followed by treatment for any identified mental health problem, after which their “suicidal” wishes are likely to change.

6.10 In a society with an aging population and an increasing financial burden on able people of working age, it is suspicious that a Bill should be suggested that would save the state money by sanctioning the killing of many of its most chronic and expensive patients.

6.11 It should be recognised that eugenics has re-surfaced in the form of the abortion and family planning lobby, euthanasia pressure groups as well as the current obsession with human genetics and weeding out the so-called “abnormal”. This Bill is a thinly veiled means of making legal the extermination of the most vulnerable and least “valuable” members of our society. It cannot be left unopposed by those who value each human person, from their conception to their natural death, as having equal worth and dignity.

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August 2003

77. Memorandum from Eli Lilly and Company Ltd (MIB 737)

CONTEXT

1. Lilly welcomes the publication of the Draft Mental Incapacity Bill. It has long been recognised that legislation is needed to set out a clear legal framework for making decisions on behalf of people who lack capacity to make decisions for themselves. Our particular area of interest is in the use of advance statements. While we welcome the introduction in the Bill of advance refusals/directives, we believe the legislation should also include provision for advance statements.

2. Lilly is one of the world's leading research based pharmaceutical companies. We are committed to researching and developing breakthrough medicines and currently provide treatments for a range of mental health disorders, diabetes, cancer, coronary heart disease, osteoporosis, severe sepsis and erectile dysfunction. Lilly is a top ten supplier of medicines to the NHS by value and as a signatory of the NHS Plan, we are committed to working in partnership with the NHS.

THE VALUE OF ADVANCE STATEMENTS

3. Lilly strongly supports the Government's aim of increasing choice for patients as we believe people should be fully involved in decisions about their treatment and care. For those who lose capacity, whether on a permanent or fluctuating basis, the ability to make an advance statement is an important means of retaining control and choice. Advance statements allow people to write down when they are well what they would like to happen were they to become unable to take decisions for themselves. They are not necessarily confined to health matters but could detail the individual's preferences in other areas of their life, such as choice about their living arrangements.

4. Advance statements can have added benefits when drawn up in consultation with clinicians and carers, as they can assist the development of a positive therapeutic relationship. Advance statements are a way of developing good practice by encouraging professionals to discuss and plan treatment with their patients, and they should be helpful to professionals in making decisions about treatment for a person who has lost capacity. They should also be helpful to family members and carers. The National Institute for Clinical Excellence has recognised the value of advance statements and encouraged their use⁴. Similarly, the Government's expert committee on mental health legislation led by Professor Richardson recommended that provisions should be included in statute and complemented by the Code of Practice to ensure:

- the creation of an "advance agreement about care" is routinely considered by care teams and patients; and
- that when created these agreements would have sufficient formality to be regarded as proper statements of a patient's capable wishes.

WHY SEPARATE PROVISION FOR ADVANCE STATEMENTS IS NECESSARY

5. The Draft Bill does not currently include any explicit reference to advance statements. When discussing the clauses on advance refusals, the Explanatory Notes state "advance statement[s] will form part of the person's 'wishes and feelings', and so would have to be considered under the best interests principle in every decision that was taken on behalf of the person who lacked capacity".

⁴ National Institute for Clinical Excellence (2002), Technology Appraisal Guidance 43: Guidance on the use of newer (atypical) antipsychotic drugs for the treatment of schizophrenia.

6. We welcome the principle that the “best interests” of the individual should be paramount in deciding care and treatment, and are pleased that the Bill makes clear that the individual’s “wishes and feelings” should be taken into account in determining what is in their best interests.

7. However, if a person has made an advance statement it should not be necessary to look at what is in their best interests, as the person has, when capable, said how he/she wishes to be cared for. Their wishes should therefore be complied with, without the need to consider what is in their best interests, unless there are good reasons for not complying (see paragraph 8). One of the principles of capacity is that people can make unwise decisions—so if someone when capable has made it clear what they would like to happen to them if in the future they become incapable, this should be complied with even if this is not considered to be in their best interests. The person’s personal choice made when capable and in the full knowledge of what the consequences of that decision is likely to be should be respected.

8. Lilly believes the Bill should include a separate clause on advance statements, requiring any advance statement to be followed save in certain circumstances. This proviso is necessary for those cases where it will not be practicable to comply with an advance statement. For example, asking for a particular form of treatment could present major difficulties and healthcare professionals should not be bound to provide the treatment requested if it conflicts with their professional judgment about the most appropriate treatment to give the person. It would therefore not be advisable to give advance statements the same status as advance refusals of treatment. However, consideration could be given to setting out the general circumstances in which advance statements could be overridden. In addition the legislation should require the reasons for not complying with the advance statement to be set out in writing (as in the Mental Health (Care and Treatment) (Scotland) Act 2003) and also state that where there are disputes in connection with advance statements these should be referred to the court.

SUMMARY

9. Advance statements are important in giving people control and choice over their future care. They express the individual’s choices made at the time when he/she had capacity. The Bill should include an additional clause to provide for advance statements and should clearly set out the circumstances in which they can be overridden.

August 2003

78. Memorandum from Rethink (MIB 739)

INTRODUCTION

1. Rethink, formerly known as the National Schizophrenia Fellowship, is the charity for people who experience severe mental illness and for those who care for them. We are both a campaigning membership charity, with a network of mutual support groups around the country, and a large voluntary sector provider in mental health, helping 7,500 people each day. Through all its work, Rethink aims to help people who experience severe mental illness to achieve a meaningful and fulfilling life and to press for their families and friends to obtain the support they need.

2. Rethink has a National Advice Service which responds to enquiries from its members and the general public on a range of issues. These include some related to mental capacity, especially appointeeship, whereby someone may be appointed by the Secretary of State for Work and Pensions to claim and receive social security benefits for a person who lacks capacity.

3. Rethink is an active member of the Making Decisions Alliance and of the Mental Health Alliance, which correspondingly campaigns on the reform of mental health legislation. We have a particular concern that there is compatibility between proposed mental incapacity and mental health legislation and a focus on people whose mental capacity fluctuates.

4. In general, we support the policies of the Making Decisions Alliance and have been involved in formulating them. Our submission concentrates on issues of particular concern to Rethink. These include fluctuations in mental capacity due to severe mental illness.

FLUCTUATING MENTAL CAPACITY AND ACCESS TO HELP

6. People with fluctuating capacity and those seeking help on their behalf have to cope with a group of problems which make access to help difficult. Many forms of severe mental illness involve fluctuating capacity, during which thinking and mood are affected by symptoms like delusions, paranoia or euphoria, etc. During such episodes, the affected person’s judgement is often impaired and the views and preferences which they hold when well are submerged, but eventually return after appropriate care, treatment and support has been provided. During episodes of severe mental illness, the person affected is likely to deny that they have mental health problems and to blame those trying to access care and help in what they perceive to

be the person's best interests. Conflict often results and relationships may be severely strained. A major problem for those seeking help is that mental health professionals often have difficulty in assessing the situation, especially at first onset, because they are likely to be misled by delusionary ideas, diverted by tensions and conflict, and have little knowledge of the person's views, preferences and presentation when well. As a result, symptoms of mental illness may go unrecognised by professionals until crisis point is reached, by which time it may be necessary to use compulsion under the 1983 Mental Health Act. Help seekers currently have no recognised status in pressing for help, and the affected person's rights to personal autonomy and confidentiality are often given as reasons by professionals when they refuse to help or intervene. In Rethink's view, early intervention is crucial, as is continuity of care.

6. Rethink believes that many of the proposals in the draft Incapacity Bill, if properly implemented, should improve the situation by creating a new legal framework in which the position of those seeking help or caring for someone with fluctuating mental capacity would be better recognised. The concept of Lasting Power of Attorney and Court appointed deputies should be helpful, although not at the first onset of mental illness which will require special consideration. We should like the new legislation—preferably both the Mental Incapacity Bill and the draft Mental Health Bill—to promote the use of a wide form of Advanced Statement which could detail a person's capacious views and preferences about the arrangements to be put in place should they be affected by a further episode of mental illness.

ADVANCE STATEMENTS

7. As we have said above, we support the Making Decisions Alliance in pressing for advance statements in which a person states their preferences, not just refusal of treatment through an advance directive.

8. Recommendations were made in paragraphs 12.12–15 of the Report of the Expert Committee (the Richardson Committee) in November 1999 that clinical teams should be expected to help patients develop advance agreements. Further, when a patient is subject to assessment and initial treatment under compulsory powers, the clinical team will be expected to take account of any recent advance agreement developed in consultation with specialist mental health services. Guidance on advance agreements would be included in the Code of Practice on the new legislation.

9. Paragraph 5.14–15 of the White Paper, *Reforming the Mental Health Act* (Cm 5016–1) acknowledge that advance agreements about the sorts of treatments an individual would prefer should they come to lack capacity, may be an important factor in determining what care and treatment is in a patient's best interests. However, neither provision for advance statements nor advance directives was included in the draft Mental Health Bill.

10. Sections 275–76 of the Mental Health (Care and Treatment) (Scotland) Act 2003 provide for advance statements that specify:

- the ways the person making it wishes to be treated for mental disorder;
- the ways the person wishes not to be treated.

11. The effects of advance statements include:

- a person giving medical treatment authorised by virtue of the Act shall have regard to the wishes specified in an advance statement
- where the Tribunal or designated medical practitioner takes a decision that conflicts with those wishes, they are required to record the reasons for this, to notify the person who made the advance statement and to place a copy of that record in the person's medical records.

12. Rethink seeks advance statements and advance directives in the Mental Incapacity Bill compatible with the proposed new mental health legislation. We also expect that if preferences are over-riden, the reasons for doing so must be recorded in writing, handed to the patient and stored in the relevant records. For patients subject to compulsory powers, we believe that an advance directive should only be over-riden by a tribunal, unless there is an imminent danger. The new Court of Protection should also take into consideration the content of Advance Statements.

13. *Overlap between the Mental Health Bill and the Incapacity Bill*

We are concerned that the two Bills propose two separate systems for substitute decision making and that if these are implemented, a good deal of confusion could result for both service users and carers. We therefore believe that it is essential that detailed consideration should be given to:

- The relationship between the new Court of Protection and the new Mental Health tribunal, as it appears that both bodies would be involved in determining best interests and settling disputes.
- The relationship between the proposed Nominated Person and the holder of the Lasting Power of Attorney or Court appointed deputy.

It is important that there should be no incompatibility between the two new systems.

14. *Assessment of capacity*

We support functional assessment of capacity, which will be set out in detail in the proposed Mental Incapacity Bill Code of Practice. As members of the Mental Health Alliance, Rethink is seeking for compulsory powers in proposed mental health legislation to be based on mental incapacity, with some exceptions for people who are at substantial risk of suicide or a danger to others. In general, people with capacity have the same choices in their mental health care as people have with physical health care needs. Rethink also believes that careful thought needs to be given to the mechanism for decision making to return to a person who regains mental capacity following an episode of severe mental illness.

15. According to the draft Mental Incapacity Bill, mental capacity will need to be determined when a particular decision takes place; in the Mental Health Bill we should anticipate any assessment of capacity would first take place in a preliminary examination prior to consideration of compulsory powers. It is important to ensure that there is compatibility between the draft Mental Incapacity Bill and Mental Health Bills and their Codes of Practice.

16. *Advocacy*

In clause 159 of the draft Mental Health Bill, the appropriate Minister must arrange, to such extent as he considers necessary to meet all reasonable requirements, for help to be available from mental health advocates to qualifying patients and to their nominated persons. This falls short of an advocate being available as of right, but we are concerned that the Mental Incapacity Bill does not provide any duty to provide advocacy support at all. Rethink believes that independent advocacy support should be provided when important decisions are being considered when mental capacity is an issue.

17. We should just add that if a person has an advocate under mental health legislation, they would need the same advocate under mental incapacity legislation, having gained trust with them.

18. *Appointeeship*

We believe that appointeeship should come within the scope of the Mental Incapacity Bill because, at present, it is an administrative procedure, which, in the experience of Rethink, is problematic. When power to claim and receive benefits is transferred from an individual with mental incapacity to someone else, they should be protected through mental incapacity legislation.

19. *Implementation*

Rethink has some concerns as to how the cost of the new proposals is to be met. We hope it will not result in a financial burden on those who come under the new legislation or their carers. If the arrangements are to be monitored adequately, this will add considerably to the cost of implementation. We would also draw your attention to the need for those implementing the legislation to be adequately trained, as well as staff in relevant organisations, and for the new arrangements to be well publicised to ensure that anyone able to benefit takes advantage of the opportunities available.

20. *Conclusion*

We have referred to our main issues of particular concern, but we welcome this Bill and are generally impressed by its content. We have attached as an annex two case studies which demonstrates the sort of problems which arise due to fluctuating capacity in someone with severe mental illness.

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Annex

Case Study: Effects of Mental illness on Capacity to deal with Financial Affairs

This case illustrates how someone with schizophrenia acquired substantial debt because there was nobody to deal with her financial affairs while she was unable to do so because of illness and hospitalisation.

Carol is a divorced single parent in her late forties and has two children in their teens. She has schizophrenia but her condition was stable for 12 years until two years ago, when she was no longer able to cope and the children asked to go into foster care. Carol was sectioned shortly after the local social services children team became involved. She has had several long admissions into hospital during the last two years, all under section 3 of the Mental Health Act. During these admissions, her benefits were reduced and as a result there was insufficient money in her bank account to pay her direct debits for fuel etc. The bank imposed a charge of £30 each time this happened and added interest, until she was overdrawn by £2,500.

Although the children were in care, Child Benefit continued to be paid into Carol's bank account. She was not normally entitled to it, except when the children came to stay with her on some weekends and during some school holidays. She is now required to pay back £1,400.

Carol now owes nearly £4,000. Her entire income is made up of Income Support and Disability Living Allowance.

Case Study: How Impaired Capacity can hinder Access to Care

A man who suffered a mental breakdown at university is now paranoid about his immediate family, who are doing their best to help him. However, he sees any support they suggest as oppressive and detrimental to his interests. He is very intelligent and can communicate well, but his views are distorted through his delusional beliefs. His family are unable to persuade the mental health professionals that he needs help. Instead they are felt to be over anxious and interfering.

79. Memorandum from the All-Party Parliamentary Pro-Life Group (MIB 740)

SUMMARY

1. The All-Party Parliamentary Pro-life Group upholds the sanctity of human life from conception until natural death. Every human being, regardless of mental incapacity, possesses a fundamental worth and dignity for as long as he or she is alive. Human worth and dignity do not depend on acquiring and retaining some particular level of understanding or capacity for choice or for communication. Recognition of the fundamental worth and dignity of every human being is the indispensable foundation of justice in society.

2. We acknowledge the need to reform the law as it relates to those who are mentally incapacitated.

3. Mental incapacity legislation must not be the Trojan horse through which assisted suicide and euthanasia are introduced. We are deeply concerned that the draft Mental Incapacity Bill would weaken the prohibition against assisted suicide and euthanasia.

4. The understanding of the pivotal concept of "best interests" must include objective, substantive requirements if vulnerable persons are not to be put at risk.

5. In order to protect the mentally incapacitated from abuse and help restore moral and intellectual clarity to the law in this area we commend to the Joint Committee Baroness Knight of Collingtree's Patients' Protection Bill. This Bill would make it an offence for any person responsible for the care of a patient to withdraw or withhold sustenance if his purpose in doing so is to hasten or otherwise cause the death of the patient. We urge the Committee to read the House of Lords debates on this Bill carefully and insert into the draft Mental Incapacity Bill provisions from the Patients' Protection Bill that relate to the mentally incapacitated.

Thank you for this opportunity to comment on the Draft Mental Incapacity Bill. We acknowledge the need to protect those who are mentally incapable and to clarify the legal position of those undertaking the care of mentally incapacitated adults who are not detained under the Mental Health Act 1983.

We also recognise the need for a common framework of law to regulate decision-making for the mentally incapacitated which embraces their health and welfare interests as well as their financial interests.

We would welcome the opportunity to appear before the Committee to submit oral evidence.

- The All-Party Parliamentary Pro-life Group is committed to upholding the sanctity of human life from conception until natural death. Every human being, regardless of mental incapacity, possesses a fundamental worth and dignity for as long as he or she is alive. Human worth and dignity do not depend on acquiring and retaining some particular level of understanding or capacity for choice or for communication. Recognition of the fundamental worth and dignity of every human being is the indispensable foundation of justice in society.
- Mental Incapacity Legislation must not be the Trojan horse through which assisted suicide and euthanasia are introduced. We are deeply concerned that the Draft Mental Incapacity Bill would weaken the prohibition against assisted suicide and euthanasia.

BEST INTERESTS—SECTION 4

1. The explanatory notes identify this concept as constituting "the overriding principle that must guide all decisions made on behalf of someone lacking capacity."

2. It is therefore imperative that this concept is accurately defined. Unfortunately the checklist of factors in the draft Bill is deficient.

3. The understanding of “best interests” must include objective, substantive requirements. The views of others on a person’s “wishes and feelings and the factors he would consider if he were able to do so” should be allowed to influence decision making for the person only if they are consistent with an objective, substantive conception of the “best interests” of the person.

4. In the area of healthcare, the concept of “best interests” should be understood to include the standard objectives of healthcare practice: the restoration and maintenance of health, or of whatever degree of well-functioning can be achieved, the preservation of life, and the control of symptoms when cure cannot be achieved.

5. If the understanding of “best interests” fails to include objective, substantive requirements there will be no non-arbitrary way of judging whether the testimony of relatives and others about a patient’s “preferences” is self-serving.

6. Objective criteria of what is in a person’s best interests excludes the thought that it can ever be in a person’s best interests to have his life ended through conduct (“action” or “omission”) intended to end his life. This denies the inherent worth and dignity of seriously incapacitated human beings.

7. In the absence of objective and substantive criteria which refer to the patient’s best medical interests, the concept of “best interests” collapses into whatever the person thinks or whatever other people think is in the person’s best interests. This does not serve to protect the mentally incapacitated.

THE GENERAL AUTHORITY—SECTION 6

8. No person acting under a general authority should be able to authorise the withholding or withdrawal of either life sustaining treatment or basic care.

9. The Law Commission draft Bill Mental Incapacity defined “basic care” as “care to maintain bodily cleanliness and to alleviate severe pain, as well as the provision of direct oral nutrition and hydration”. [LawCom231: 5.34] We believe this definition is too narrow. Nutrition and hydration, however so delivered, should be considered a part of basic care. They are not a form of medical treatment. Hunger and thirst are not illnesses. The provision of appropriate sustenance is necessary to sustain life.

LASTING POWERS OF ATTORNEY—SECTIONS 8 TO 13

10. Legislation introducing LPAs extending to personal welfare and health care matters is welcome only if the LPA is exercised by reference to the “best interests” of an incompetent person, with the concept of “best interests” being understood by reference to objective and substantive requirements as set out above.

11. No attorney should have the power to consent to the withholding or withdrawal of basic care which includes appropriate nutrition and hydration, howsoever delivered.

ADVANCE DECISIONS TO REFUSE TREATMENT—SECTIONS 23 TO 25

12. We do have serious concerns that the proposed legislation on advance decisions to refuse treatment would undermine protection for the mentally incapacitated.

13. Advance decisions will encompass matters of profound significance in terms of personal welfare and health care. There is a need for clarity and accuracy. Advance decisions “expressed in broad terms or non-scientific language” (Section 23(2)) are likely to fail to satisfy these criteria. They could be dangerous and compromise patient care.

14. Oral advance decisions or advance decisions dealing with hypothetical future scenarios may lead to disputes which the courts would be called upon to resolve. An increase in litigation consuming scarce health care resources would be an unfortunate by-product of legislation.

15. There is no requirement in the draft Bill for the maker of an advance decision to seek medical advice prior to finalising his advance decision. An ill-informed advance decision can hardly be considered a genuine exercise of autonomy.

16. Advance decisions to refuse treatment must be framed by reference to the “best interests” of an incompetent person, with the concept of “best interests” being understood by reference to objective and substantive requirements as set out above.

17. Assisting in suicide is an offence in the United Kingdom. It is important that the law should continue to discourage assistance in suicide, even when the assistance takes the form of omitting care and treatment, in accordance with the terms of an advance refusal of treatment.

18. Doctors and other carers should not be obliged to comply with advance decisions to refuse treatment that are suicidally motivated. To oblige doctors and other to do otherwise, fatally undermines the legal prohibition against assisted suicide and is contrary to the patient’s “best interests”, properly understood.

19. Rather, doctors and other carers should be obliged to act with a view to serving the best interests (including sustaining the life) of the mentally incapable person, just as if no such refusal had been made.

20. To legitimise advance decisions to refuse treatment or care with a view to ending life is morally indistinguishable from euthanasia. Proponents of euthanasia will argue that active, or positive, euthanasia is more merciful than what can be a protracted and painful death where life-sustaining treatment or care is withdrawn.

21. A person's refusal of life-prolonging treatment need not be motivated by the desire to end his life. It can be reasonable to refuse such treatment on the grounds that burdens associated with the treatment outweigh the benefits. In assessing the likely burdens of a course of treatment for a mentally incapacitated person consultation can take place with relative and friends. Advance decisions which, although not binding, fulfil criteria of clarity and accuracy can play a useful role in informing doctors of a person's wishes.

22. It should not be possible for advance decisions to refuse treatment to exclude the provision of basic care, including the provision of nutrition and hydration, howsoever delivered. Nutrition and hydration can be delivered to persons in a variety of different ways, at different times and for different periods of time. We cannot envisage how an advance decision to refuse such basic care can be expressed with sufficient clarity and accuracy so as to exclude the possibility of a mentally incapacitated person being deprived of the basic necessities of life in circumstances where the provision of such basic care is appropriate and not unduly burdensome.

CONCLUSION

23. The All-Party Parliamentary Pro-life Group acknowledges the need to reform the law as it relates to those who are mentally incapacitated.

24. The understanding of the pivotal concept of "best interests" must include objective, substantive requirements if vulnerable persons are not to be put at risk.

25. The draft Mental Incapacity Bill would authorise those responsible for care of the mentally incapacitated to withdraw or withhold medical treatment or nutrition and hydration, however delivered, with the purpose of hastening or otherwise causing the death of such individuals. Following the House of Lords judgment in the Anthony Bland case such conduct may well be deemed as compatible with the exercise of the duty of care for a person if doctors judge that person's life no longer worthwhile.

26. In the words of Lord Mustill, the law in this area is "both morally and intellectually misshapen." To allow doctors or attorneys to withdraw medical treatment or sustenance from the mentally incapacitated with the purpose of ending their lives subverts the law of murder.

27. This does not mean that medical treatment cannot be withheld or withdrawn when it is considered that the burdens of such treatment outweigh the benefits, or that sustenance cannot be withheld or withdrawn from a person what is in the process of dying and where the placement of feeding tubes would be regarded as unduly intrusive and inappropriate or where the risk of placing the feeding tube would be excessive.

28. In order to protect the mentally incapacitated from abuse and restore moral and intellectual clarity to the law in this area we commend to the Joint Committee Baroness Knight of Collingtree's Patients' Protection Bill. This Bill would make it an offence for any person responsible for the care of a patient to withdraw or withhold sustenance if his purpose in doing so is to hasten or otherwise cause the death of the patient. We urge the Committee to read the House of Lords debates on this Bill carefully and insert into the draft Mental Incapacity Bill provisions from the Patients' Protection Bill that relate to the mentally incapacitated.

August 2003

80. Memorandum from the Association for Palliative Medicine of Great Britain and Ireland (APM) and the National Council for Hospice and Specialist Palliative Care Services (MIB 742)

INTRODUCTION

1. This response is focussed on the clauses dealing with advance decisions, these being our area of expertise both as medical practitioners in specialist palliative care and as ethicists⁵.

2. Overall we welcome the principles which underlie the proposals in these clauses. In particular, we are pleased that the draft Bill addresses the problems which arise when health care professionals have to make decisions on behalf of those who lack capacity; that it allows for an LPA for health and welfare matters; that it addresses the status of advance decisions to refuse treatment; and that it provides a potential legal framework within which advance decisions can be operated.

⁵ Harrison MAM Advance Directives: a critical examination PhD thesis, University of Keele 1997.

3. However, we are concerned that, in their present form, the actual proposals are bland and undefined and unlikely to serve truly the best interests either of patients or of health care practitioners. In particular, the clauses are so widely drawn that, if they were to come into force without supporting codes of practice or guidance, they would in practice be almost unworkable.

DECISIONS MADE UNDER THE GENERAL AUTHORITY AND POWERS OF ATTORNEY

4. The important areas here relate to those who have never had capacity and to those who have, for whatever reason, not made an advance decision.

5. More guidance is required for those who will make treatment-related decisions on behalf of those without capacity. These individuals include those who act under a lasting power of attorney, those who are designated by the Court as an appointed deputy and those clinicians who may meet the person without capacity for the first time when such a decision is required.

6. We note that clause 4 of the draft Bill sets out some guidance for clinicians (and others) when assessing a person's best interests. We would suggest that the views of donees of LPAs should take precedence over those who might have cared for a person in some minor respect, but whom the individual in question had chosen not to appoint as an attorney.

7. It should be recognised that there cannot be a single pro forma for these decisions which can never entirely encompass what are highly personal judgements.

8. Our particular concern, in this context, is to protect the interests of patients who have a long-term, or regular but intermittent lack of capacity. Although the primary focus of the draft Bill appears to be on persons with chronic incapacity, it will clearly also apply to persons with physical illness(es) which may cause either confusion or impairment of consciousness. Such situations frequently render patients incapacitated in making health care decisions, either temporarily or permanently. In the context of palliative care such incapacity may be a predictive event, but it may also be unexpected with a sudden onset.

9. The draft Bill requires decision-makers to form an assessment about an individual's best interests. That assessment will inevitably involve judgements surrounding the individual's quality of life, in particular the question whether or not, when reviewing all the circumstances and potential outcomes that the individual faces, that life would be considered by the patient to be worth living in the future.

10. An individual's view of disability and quality of life changes as he progresses along the disease or disability journey. Individuals are able to adjust to living with conditions and outcomes which, to a healthy individual, would make life intolerable. It is essential that decision-makers form perspectives which take account of that.

11. This is relevant to advance decisions as well. We would hope that any code of practice would include a proposal that an individual should regularly revisit his advance decision to keep it up to date and ensure that it reflects any evolution in his attitudes as he progresses along the disease path.

ADVANCE DECISIONS

12. General guidance for establishing advance decisions has already existed for some time. It clearly states the requirement that the individual must have capacity at the time of making the decision⁶. We note that the draft Bill reflects that position.

13. It is welcome that the draft Bill establishes the means by which a framework to operate advance decisions can be created. However, we note that there is currently very little detail about how advance decisions would work in practice.

14. We suggest that either more detail is included in the draft Bill concerning the proper drafting of and interpretation of oral or written advance decisions or that a Code of Practice is issued as soon as possible to guide professionals, carers and appointed proxies. This should be considered alongside the draft Bill before it is presented to Parliament, remembering that the Code of Practice for the Mental Health Act 1983 was not issued until 1990—hardly helpful in the interim for patients or those charged with caring for them. We would not welcome such a delay applying to this draft Bill.

15. We note that, unlike some of the other issues covered by the draft Bill, there is no requirement for a code of practice to be issued in relation to advance decisions. That is a significant flaw; the current proposals need further detail and guidance before they would be workable. A code of practice is essential before the clauses dealing with advance decisions come into force. As the draft Bill currently stands it would be possible to bring the clauses providing for advance decisions into force without any supporting code of practice. That would cause us great concern.

16. Given that so much about the detailed operation of advance decisions has been left to a future code of practice, we believe that, if Parliament is to be able to scrutinise effectively the practical impact of this legislation, the codes of practice should be considered alongside the draft bill.

⁶ BMA Advance Statements about Medical Treatment BMA 1995, reprinted 2000.

17. We also note that members of the Mental Incapacity Consultative Forum were told⁷ that lessons had been learned from the Scottish experience, in particular about the difficulties which arise when the publication of codes of practice is left until after the passage of the primary legislation. That experience should not be repeated here.

18. In particular, the following issues need to be addressed, either in the primary legislation, or in a code of practice:

- (a) What form should advance decisions take, both in terms of their recording or reporting, and any subsequent amendments or withdrawals, as well as in terms of the required detail or clarity? For example, how would an oral amendment to a written decision work? As specialist palliative care practitioners, we frequently work with oral advance decisions, recording these in the patient's case notes—we would not wish to endorse the implication that incapacitated people will be expected to have drafted written advance decisions—as is the case in the Scottish legislation.⁸
- (b) What level of detail will be needed to enable a clinician to give effect to an advance decision?
- (c) Should oral and written advance decisions be witnessed and, if so, by whom, and by how many people, and from what disciplines?

19. There should also be clear reference to the fact that no advance decision can request any illegal act such as euthanasia or physician assisted suicide and also that physicians are not obliged to offer treatments which they believe to be clinically inappropriate.

20. The emphasis of the draft Bill is on decisions to refuse specific treatments. However, the sense of advance decisions is often to exclude life-sustaining or life-prolonging treatment more generally—not to focus on specific clinical procedures. It is difficult, almost impossible, for a patient to draw up a “shopping list” of treatments that he would wish to refuse, before knowing what might be relevant to the conditions that befall him.

21. The solution might be to distinguish between specified treatments and treatment more generally, and in particular to define what the Bill means by “life-sustaining treatment”. We note that in the Scottish legislation “medical treatment and life-sustaining treatment” includes:

- (a) surgical, medical, optical or dental procedures or treatment;
- (b) ventilation, nutrition and hydration by artificial measures;
- (c) any other procedure or treatment designed to safeguard or promote physical or mental health.

Advance decisions should only relate to (b) above if the individual specifically states that is to be the case.

22. We would be willing to offer oral evidence to the Committee should that body consider this appropriate.

August 2003

81. Memorandum from Cardiff People First (MIB 746)

We think the bill will be helpful for people:

- who are traditionally recognised as being able to make decisions, then for some reason lose that capacity;
- who have never had the capacity to make decisions.

The bill will not be helpful for people;

- who traditionally were not viewed as being capable of making decisions for themselves, people with a learning disability.

We are an organisation for people with a learning disability, led by people with a learning disability. Members find that many people think they are not capable of making decisions when they are. Many members find other people decide for them. Some people will make decisions which suit them, not the person with a learning disability. So some people with a learning disability are afraid that staff/parents/carers/others will use the Bill to boss them around, stop them from doing things and make them do things they don't want to.

The Bill is clear what happens in cases where the person does not have capacity to make decisions. But we would like to ask what happens when the person is capable of making decisions but does not have the opportunity to do so or is not allowed to? Going to court seems a bit heavy.

⁷ Meeting 14 May 2003.

⁸ Mental Health (Care and Treatment) (Scotland) Act 2003.

More needs to be included in the Bill to protect the rights of people with a learning disability to make their own decisions. Services are needed to support people to make those decisions. The public need to know that people with a learning disability are capable of making decisions for themselves unless proved otherwise.

We liked the idea that the Bill assumes people have capacity unless determined otherwise. At the Department of Constitutional Affairs workshop in Cardiff in July it was explained that the Bill over time hopes to change attitudes to decision-making by people with a learning disability. This is good. But the Bill needs to do more to protect that right to make decisions until attitudes have changed.

Also, the Bill is okay if people stick to the rules. If people don't, there needs to be an accessible complaints procedure. More independent advocates are needed, to support people who can make their own decisions but find others don't listen or won't let them make decisions.

We would also like to ask who decides if a person is incapable of making decisions for themselves? Some people with learning disabilities are worried that just anybody who claims to have their best interests in mind will be able to take over their lives. So how is this decided? Would there be checks to make sure this did not happen? How do people complain if they disagree with the decision?

It is important that the judges in the Court of Protection and Public Guardians are chosen carefully and have experience of these issues.

We would also like to ask, who is going to decide when the deputies take over making decisions from people?

We do not like the term Mental Incapacity.

If the bill becomes law, our ideas for telling people about this are:

- Television/adverts
- Radio
- Helpline
- Mobile information unit
- Social workers/doctors etc.

August 2003

82. Memorandum from Carers UK (MIB 771)

SUMMARY

(i) Carers UK is an organisation of carers, run by carers, for carers. We provide information and advice, carry out research and seek changes from policy makers that will improve carers' lives.

(ii) Carers are people who provide care to a relative, partner or friend because they are frail, chronically sick or disabled. The care they provide is unpaid. There are six million carers throughout the UK and their support has been valued at an estimated £57 billion a year.

(iii) Carers UK welcomes the publication of the draft Bill and believes that it will help to solve many of the problems faced by carers in providing support to a person lacking capacity to make certain decisions. However, amendments are needed to improve the Bill.

(iv) Carers will be affected in three major ways by the Bill. First, the degree to which they are involved in decision-making and their views taken on board if they have significant knowledge about the person lacking capacity. Second, the decisions that professionals make on behalf of the cared for person directly impact on the carers' life and it is vital that their needs are considered. Finally, the legislation could provide a sounder and clearer legal basis on which carers can make decisions.

(v) In short, Carers UK recommends the following changes to the Bill:

- at present, Clause 4 does not distinguish between a carer and paid professional and it is vital that it does;
- there is no hierarchy of decision-making in Clause 4 so equal weight could be given to a full-time carer's views, as they would to a care assistant who visits once a week for half an hour;
- a safeguard to ensure that carers' views are taken on board if they are not a Donee or Deputy. This could take the form of a sub-clause to state that they must have regard to the carer's views if a decision is likely to impact on them. This would make the legislation compatible with the Human Rights Act 1998.

1. ABOUT CARERS UK

1.1 Carers UK (formerly Carers National Association) is an organisation of carers, run by carers, for carers. We represent the views and interests of the six million carers throughout the UK. Carers UK provides information and advice to carers and we respond to around 20,000 enquiries annually. Through our wider network of Associates, we are in touch with around 300,000 carers.

1.2 We regularly ask carers about all aspects of caring and encourage them to articulate their needs and experiences to us. Their recommendations and this research inform our policy, on which this response is also founded.

1.3 Carers UK is a member of the Making Decisions Alliance.

2. CARERS UK'S MAIN VIEW OF THE BILL

2.1 We welcome the publication of the Bill for two main reasons. First it begins to address some of the problems that carers face in caring for a relative, partner or friend who, for a period of time, lacks capacity. Second, Carers UK has called for legislation on mental incapacity for some time and it is vital that it is introduced in advance of any new Mental Health Bill as so much of the latter is dependant on establishing capacity.

2.2 However, there are elements which concern us and that we believe to be neither workable nor practical. We are concerned that lack of clarity and definition will result in poor practice not only for carers, but also for the people they care for. In our response, we have tried to focus on how these issues might be addressed.

2.3 There are currently six million carers throughout the UK.¹ However, not all these carers will provide support to someone who lacks capacity. The vast majority of carers will be caring for someone with solely a physical disability. However, according to the General Household Survey (GHS), one in four carers (24 per cent) provides support to someone with a "mental disability".² The GHS does not define mental disability, nor does it look at the level of capacity of the person being cared for.

2.4 It is likely the majority of carers will welcome more clarity in the law. Is it possible that some carers will view some of the new procedures as burdensome and it is important to ensure that there are not unreasonable or unnecessary demands placed on carers. Our response to the powers of general authority (clause 6) discusses this in more detail. One concern of carers is likely to focus on cost, particularly the costs of applications and resolutions of disputes through the Court of Protection.

3. OBJECTIVES AND PROBLEMS—CARERS

3.1 One of the key objectives of the Bill, as set out in the paragraph 4 of Annex A of the Partial Regulatory Impact Assessment, is to address the problem that many carers face; namely that while they often have the best interests of the person that they care for at heart, they have no clear protection in law for the decisions they take.

3.2 The other problems that carers experience are difficulties in accessing information, such as medical information because there is no clear legal framework underpinning sharing of information. There are also times when carers are acting in the best interests of the person they care for but disagree with a professional. Our members tell us that often professionals are more readily listened to, than carers. This is true not only of major decisions such as where to live, medical treatment, etc, but also of day-to-day decisions about the way that people are cared for, what they have enjoyed doing, etc.

3.3 One of our members has cared for her two daughters with severe learning and physical disabilities for over 25 years. The local authority disagreed that the parents were acting in the daughters' best interests, wanted to place them in residential care and went to court to remove them from the parents' care. The local authority's proposal would also have involved moving the daughters with hoists, which they dislike intensely and stopping certain activities which the local authority deemed too difficult—such as swimming once a week. The parents also take them out quite frequently on different activities. The Official Solicitor appointed to advocate on their behalf of the two young women, conducted an independent assessment into the situation. They concluded that the local authority's plan would have been worse for the two women and the Official Solicitor won the case against the local authority.

Definitions in the Bill

3.4 Another major problem with the Bill's drafting is that it does not distinguish between carers ie those who give support to a chronically sick, disabled or frail partner, relative or friend and those people who provide care as part of their employment or as a volunteer. This is inconsistent with other legislation to date, namely the Carers (Recognition and Services) Act 1995, Carers and Disabled Children Act 2000, Community Care (Delayed Discharges, etc, Act 2003 and draft Mental Health Bill all of which make clear distinctions in primary legislation between the two groups.

3.5 There are several practical reasons why the Bill needs to distinguish between these two groups. Carers are people who provide the bulk of care to people who are chronically ill or disabled in the community. The care they provide is estimated at £57 billion per year.³ If they provide substantial amounts of care over a period of time they gain significant knowledge and insight into the condition of the person they care for. Carers want to be seen as partners in care and want to contribute to decision-making about the person they care for.

3.6 The other important aspect of caring is the impact that decision-making has on the carer's own life. Caring already takes a significant toll on health, well-being and household finances. In one survey, half of the carers providing significant amounts of care had sustained a physical injury since becoming a carer, and half had been treated for a stress-related illness.⁴ Carers are statistically more likely to suffer from ill-health than non-carers.⁵ Another survey found that 77 per cent of carers providing full-time care had their financial situation affected by caring.⁶ The same survey showed that the more care a carer provided and the longer they provided long-term care, the more likely they were to be in receipt of Income Support and have less than £1,000 in savings. The Census estimates that around 200,000 carers currently work full time and care for over 50 hours per week, spending almost every hour outside of work caring.⁷ In one Carers UK survey of its members, six out of ten had given up work in order to care and this rose to nearly eight out of ten for those aged 56 to 60.⁸

3.7 Carers are often closely related to the person they care for but it is important to distinguish between a family member who might take an interest in care, but not provide care. Those providing the most substantial amounts of care are most likely to live with the person they care for and be their partner. In other words, they are likely to have more knowledge than paid staff in terms of the person's preferences, likes and dislikes.

3.8 Carers provide a range of care. This includes physical tasks such as moving, bathing, washing, dressing, shopping, transport and feeding and financial tasks such as managing finances, payment of bills, ordering of equipment, etc. The aspects of care most commonly overlooked are those to do with organisation of care and emotional and psychological care. Organisation of care includes making appointments, arranging and cancelling care, assessments, form filling, discussion with professionals, etc. Emotional and psychological care includes reassurance, encouragement to continue to keep up medication regimes, reminding of events and tasks, regularly checking in with the person to see how they are etc. The organisation of care and emotional aspects of care can be substantial and can be regular in that they are regularly carried out or there is regularity during a period of illness. This level of care distinguishes the carer, whatever relationship they might be to the person being cared for, from an interested family member who may not be providing any care. Carers UK does not represent the latter.

3.9 Decisions and actions that paid staff make in relation to the mentally incapacitated person directly impact on the carer's life. For example, a decision to change the care assistant's rota frequently for a man with Alzheimer's Disease means that the carer has to teach the care assistant each time how to move, handle, talk to her husband. Her husband finds change stressful and it makes him very anxious and she has to spend more time reassuring him.

3.10 Carers often tell Carers UK that professionals do not respect their judgement, their knowledge about caring, or the preferences of the person that they care for. For example, when a young woman with severe learning disabilities went into residential respite care for a short period, her mother briefed staff about how to reassure and support her daughter if she became distressed. Her daughter became distressed on several occasions, the staff were unable to reassure her and demanded that the carer come and take her daughter away because she had become "unmanageable". The carer contacted Carers UK to take a complaint because the advice she gave staff had been ignored and her daughter's experiences of respite care were extremely poor. Her break, the first for several years had been cut short and she now feels that she cannot take a break again because her daughter's quality of care was so bad. The carer's own health is now severely at risk because she cannot take a break.

3.11 Carers often feel that there are big differences in the way that decisions are made. For a professional, they make a decision about the care of a person, but they do not have to live, day-to-day with the consequences of that decision. They may change jobs, move out of the area, retire, etc. Carers' lives, on the other hand, are directly affected by even the smallest decision to change food, dress, etc. because of the way that the person they are caring for will react to it.

3.12 We do not believe that it was necessarily the intention of the Department to confuse the two groups since the documentation supporting the draft Bill alludes to decision-making made by carers ie family members and friends who provide support unpaid. However, the way that the Bill is drafted would have unforeseen circumstances.

3.13 It is vital that the Bill separates out these two groups of people in order to ensure that carers needs are not overlooked and that their views are given proper weight in decision-making. This would affect several parts of the Bill.

4. BEST INTERESTS

4.1 Carers UK welcomes the principle of Clause 4, which already exists in good practice and common law, that anyone acting on behalf of the person lacking capacity must be acting in their best interests.

4.2 Clause 4(2)(d)(ii) currently states that “any person engaged in caring for him or interested in his welfare” should be consulted where a person does an act or makes a decision on behalf of the person who lacks capacity. Carers UK is concerned that this gives equal decision-making weight to both professionals and to carers.

4.3 The Clause, in that subsection, also goes on to list Donees, Deputies of the Court and any other person named by the person as someone to be consulted. There is no decision-making hierarchy in this section, which Carers UK would like to see rectified. For example, the drafting of this section gives equal weight to the views of a care assistant who visits twice a week for half an hour to help bathe a person with dementia as it does to the carer who provides support 24 hours a day, seven days a week.

4.4 In addition, the Bill needs to give consideration to the fact that the impact of decisions made in the best interests of the person without capacity have to be considered in the context of the carers’ own human rights under the Human Rights Act 1998. For example, a man with dementia refuses all care and only lets his wife care for him. Even when she does, he can be aggressive towards her. He is awake several times in the night, and walks around the house during the night and his wife has not had a full night’s sleep for several years. He is doubly incontinent and has difficulties eating. His wife has cared 24 hours a day, seven days a week for many years and she is exhausted. Her GP has told her that there is nothing he can do to help as her husband refuses help. All other avenues of help explored have met with the same response. As is common to many caring situations, relatives and friends no longer visit because they are frightened of his behaviour and find his disabilities difficult to deal with. They both have had little or no outside social interaction for years. When he falls, he is admitted to A&E and his wife refuses to have him home. Professionals consider it in his best interests to go back home. However, to discharge him back home without support, could contravene his wife’s own human rights under Article 8, a right to private and family life. Carers UK believes that the Bill needs to give further consideration to this matter.

4.5 Carers UK recognises that a Deputy or Donee may be empowered to make decisions on behalf of the person without capacity and that this provides a more secure legal basis than currently exists. Where this person is not the carer, and the carer may choose not to be this person because of the complexity, etc. Carers UK believes the carer must be consulted. The draft Mental Health Bill has set out a similar framework where the carer must also be consulted alongside the Nominated Person—if they are not one and the same person.

4.6 In conclusion, Carers UK would recommend the following changes to Clause 4:

- a separation in definitional terms between a carer and a paid professional;
- a hierarchy of decision-making;
- a safeguard to ensure that carers’ views are taken on board if they are not a Donee or Deputy. For example, the inclusion of a sub-clause to state that they must have regard to the carer’s views if a decision is likely to impact on them. This would make the legislation compatible with the Human Rights Act 1998.

5. GENERAL AUTHORITY

5.1 Carers UK understands the objectives behind the clause on general authority, but also envisages a number of tensions with it. There are likely to be a large number of carers acting day-to-day under general authority. It is vital that the guidance on the Bill, when published, establishes what is reasonable and practicable in terms of consultation to satisfy the conditions of Clause 4. For example, we would consider it neither reasonable nor practicable for the carer to consult a list of people to see what would be in the person’s best interests if the carer, who was also the person’s wife, wished to change their bath to a shower. However, if a care assistant were to change the regime of the person being cared for, for example, certain new or different foods, we would expect them to consult the carer.

5.2 Similarly, Carers UK appreciates the practicalities behind allowing people acting under general authority to commit expenditure. However, there are potential tensions. For example, a family on a very tight income, would not welcome a care assistant purchasing a piece of equipment for the person without capacity, without consulting the family, whilst expecting the family to reimburse them for the expenditure.

6. MAKING ASSESSMENTS AND CHALLENGING DECISIONS

6.1 Carers UK is concerned that there is little detail in the Bill about who is responsible for carrying out the capacity assessment of the person and how this is determined. We recognise that it would be inappropriate for primary legislation to set out too much detail. However, we would recommend that the Bill addresses this aspect. This is particularly important to ensure that the person lacking capacity either permanently or temporarily, is given a fair assessment. Carers, equally, need confidence that the assessment will adhere to the same standards.

6.2 Similarly, the Bill does not set out a framework to demonstrate who has authority to decide what is in the best interests of the person lacking capacity. Whilst the Court will take a final decision over any disputes about best interests, we feel it is vital to ensure that there is clear decision-making before this stage. This is vital not only for professionals but also for any carers and advocates working with and on behalf of people lacking capacity. For example, if the carer disagrees with a professional's view of what is in the person without capacity's best interests, how would they go about challenging this decision? Again, if the carer disagrees with a decision about what is in the person's best interests, where does this dispute start to be resolved?

7. INTERACTION OF THE BILL WITH THE DRAFT MENTAL HEALTH BILL

7.1 Carers UK believes that it is vital that the two Bills work together and welcomes the fact that the Committee will look at their interaction.

7.2 Carers UK believes that, although the Bill excludes situations where a person is under the Mental Health Act 1983, there are instances where there would be crossover. For example, someone who makes provision for a Donee to take over their affairs when they lack capacity, and they are subject to a provision under the Mental Health Act, if they lacked capacity, they would, presumably, have already empowered someone to take certain decisions on their behalf.

7.3 For carers, the interaction of the two Bills will become even more complex if there is no clarity about overlap. For example, a situation could arise where there was a Donee or Deputy, a carer, and a Nominated Person (under the draft Mental Health Bill), all with various levels of decision-making. Under the current Mental Health Act 1983, this would also include the Nearest Relative, who is not necessarily the carer. Carers are usually the only people to liaise between all professionals and they often complain that professionals do not share information nor "talk to each other". This often results in vital information being missed, information having to be repeated and poor care of the person being cared for. Who is then empowered to make decisions which are in the best interests of the person being cared for would become increasingly complex.

8. CONSULTATION PROCESS PRECEDING THE PUBLICATION OF THE DRAFT BILL

8.1 Carers UK does not have any criticisms of the way that the consultation period was carried out in preceding the publication of the draft Bill.

8.2 Carers UK has welcomed the fact that the Bill is being published in draft form as it believes that this provides an opportunity to rectify some of the problems with the Bill.

9. CONCLUSION

9.1 In conclusion, therefore, Carers UK welcomes a number of aspects of the Bill, but believes that further work needs to be carried out. In particular, this must ensure that the Bill appropriately distinguishes between carers and paid professionals to ensure the right balance of care and decision-making between the two groups.

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August 2003

83. Memorandum from My Life Choice Association (MIB 777)

We are a self-advocacy group made up of people with learning difficulties. We have talked about the draft Incapacity Bill in our local groups and at our Open Meeting in July. We are worried about the bill; this is what people have said:

"This law is a problem, lots of deaf people with learning difficulties will have a big problem with their choices and rights. Also, black and Asian people with learning difficulties and deaf/blind people with learning difficulties."

"People with learning difficulties should have the power to make difficult choices."

"Who has the money? People with learning difficulties pay Social Services to look after us, so we should have the control to make decisions."

"This law will not encourage people to find different ways of communicating with people with learning difficulties."

"Advocates CAN be good IF they listen, really get to know the person and get good information about a decision."

"The fact of life is that a lot of carers, etc are not good at listening or finding different ways to communicate. Will this Bill mean a quick way to make a decision for someone that is more about what the carer, etc wants?"

"The title is bad. It is hard to understand and is negative. It should be called something positive, like 'decision making.'"

"They should never separate a baby from its mother, even if the mother can't speak."

"This Bill may get rushed through, which means people get pushed out!"

"The Government should have asked people like us what we think FIRST."

"There hasn't been enough time for us to give feedback, ideas, etc."

"It makes us worried about our rights."

We unsure about what the law would mean to people:

"Will it become an easy way for people with learning difficulties to be told, 'you will do this?'"

"What happens if someone makes a decision you don't agree with?"

We had some positive comments about the bill:

"This Bill may help those people who are unable to make some decisions, who otherwise would be unable to get on in life."

"We would like to talk to people about the Bill like someone from Parliament."

"It writes down that you need to put effort into asking people with learning difficulties what they think."

"In our lives, people shouldn't do it, but should support us to do it."

We hope that you will listen to our comments and think about our concerns carefully.

August 2003

84. Further memorandum from the British Institute of Learning Disabilities (BILD) (MIB 782)

1. BILD welcomes the draft Mental Incapacity Bill. Many people with a learning disability find it difficult to make decisions which involve weighing up the pros and cons of different options. However, most of them can take an active role in decision-making if they are given the right help. It is important that people who need help to make good decisions have their rights and interests protected in law.

2. BILD strongly supports the introduction of a functional approach to decision-making and recognition of the fact that a person's ability to make a decision may fluctuate over time and that he or she may need relatively little help to make some decisions, but a great deal of help to make others.

3. BILD does believe that the concept of "capacity" will work in the best interests of people with a learning disability. Furthermore, "capacity" is inconsistent with a functional approach to decision-making. The functional approach would recognise that everyone (whether or not they have a learning disability) seeks information and advice from others before making an important decision. In general the more important the decision, the more extensive and formal will be the process of seeking information and advice. People with a learning disability need more help than those who do not have a learning disability. The greater the severity of the learning disability the more help someone will need. In our view, a law which instantiates the concept of "incapacity" as an arbitrary cut off point is likely to reduce participation in

decision-making for those who are most disabled. The main defence for the use of “incapacity” is to afford protection to vulnerable people. In our view the arrangements for the assumption of general authority to act by carers will not achieve this (see below).

4. Clause 2 of the Bill sets the criteria for decision-making capacity. However, application of the criteria involves the use of “all practicable steps to help him” (make a decision). In our view the explanatory notes are extremely superficial. We hope that the Code of Practice will provide a very much more detailed account of what “all practicable steps” might mean. When the Code of Practice is drafted we recommend that both BILD and the Royal College of Speech and Language Therapists are consulted. We recommend that those providing support for decision-making are encouraged to record the different ways in which a person has been assisted in the decision-making process and the outcome in terms of their response. This applies equally to people who are deemed to have capacity to make a decision as much as to those who are deemed not to have capacity. The method of recording might be notes on paper, photographs, a video or an audio tape.

The Code of Practice will need to recognise that over time new approaches to supporting choices will be developed. What is acceptable as “all practicable steps” in 2003 or 2004 will probably not be acceptable in 2013 or 2014.

5. Clause 4 requires states that any decision made on behalf of a person who lacks capacity must be in the person’s best interests. BILD welcomes the emphasis on involving the person as far as possible. We recommend that the Code of Practice provides detailed guidance on how a person with a severe learning disability can be involved in decision-making. BILD has already published advice on this topic¹ and we hope that the Code of Practice will build on this work. We also recommend that the Code of Practice suggests ways in which the person’s participation in the decision-making process can be fully documented.

6. Clause 6 sets out the general authority under which another person may make decisions on behalf of a person who lacks capacity. BILD welcomes this as an improvement on current practice where no one is legally empowered to make decisions on behalf of a person who lacks capacity.

However, we would draw attention to serious weaknesses in this part of the Bill:

- (a) First, it appears to us that a person who has general authority is also likely to be the person responsible for determining that a P lacks capacity. Anyone who needs help to make decisions is unlikely to resist or contest the views of a carer who deems them to be lacking capacity. If the person with general authority fails to offer opportunities for P to engage in decision-making, his or her judgement (about P’s lack of capacity) will become a self fulfilling prophecy. This will not be in P’s best interest.
- (b) Second, the guidance notes make it clear that no one person will be the holder of general authority. The examples given suggest that each person with general authority will act in isolation. In practice it is likely that different people, each of whom might assume that they hold general authority, will be involved in making (or helping P to make) decisions. In many situations this will contribute to the quality of the decisions being made. But what if different people with general authority disagree? For example, family carers may hold different views from the family doctor. BILD recommends that the Code of Practice includes advice on how different interpretations of “best interest” among those with general authority should be reconciled.

7. Clause 7 describes restrictions on the general authority. 7.1(b) states that a person with general authority may restrict liberty or movement if he/she believes that it is necessary to avert substantial risk or significant harm to P. BILD recommends that the Code of Practice draws attention to related guidance issued by the Department of Health and the Department for Education and Skills on the Use of Restrictive Physical Interventions². It should also clarify whether the provisions of healthcare, including dental examinations and treatment, is included within the meaning of 71(b).

8. BILD welcomes the fundamental changes signalled in this Bill. However, if the proposed changes are to make an impact on the lives of vulnerable people who need skilled and patient support in order to participate in decision-making, it is important that legislation is followed by an extensive and intensive programme of education and training. BILD recommends that when this Bill becomes law, the Court of Protection and the Public Guardian’s Office are provided with funding to organise (or commission) an educational programme to raise awareness and provide practical training for all those who may be required to act with general authority under the Act.

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August 2003

85. Memorandum from The Baroness Masham of Ilton (MIB 790)

I greatly welcome the opportunity to share my views on the Government's Draft Mental Incapacity Bill with the Committee.

I must declare a personal interest in this subject.

I had an accident nearly 45 years ago. I was taken to the casualty department of an accident hospital with a fractured spine, a suspected fractured skull, several fractured ribs, internal haemorrhage and semi-conscious.

The doctor on duty, after examining me, said to my fiancé, "If she lives through the night she will never move again."

One of the great dangers of advance decisions (section 23ff) is that it is virtually impossible to predict in advance what one will do in a situation not previously experienced.

Let us imagine the scenario of a young man who, having seen one of his friends die after a long and distressing struggle with brain cancer, signs an advance decision stating that "if I become mentally incapacitated, I do not wish my life to be sustained."

Many years later, a road accident leaves him unconscious for several days. Both doctors and relatives wish him to be provided with standard, simple treatment and care that will sustain his life until he becomes conscious again, such as sustenance through a tube, artificial ventilation and a blood transfusion.

However, because the new Mental Incapacity Act section 50(1) defines treatment as including "a diagnostic or other procedure"; because section 24(5) allows advance decisions to apply to life-sustaining treatment; because the courts (in Bland) have defined sustenance through a tube as "medical treatment"; and because the man's advance decision "expressed in broad terms or non-scientific language" is nonetheless legally binding (section 23(2)), his advance decision prohibits such simple treatment and care.

The man therefore dies, even though he was not terminally or incurably ill. He had unwittingly caused his own death because a dangerous law exploited his understandable fear of cancer.

Even if this patient, instead of being incapacitated by a road accident, had in fact contracted brain cancer, his advance decision may have—in the words of the 1994 report by the House of Lords Select Committee on Medical Ethics—"deprived the patient of the benefit of the doctor's professional expertise and of new treatment and procedures which may have become available since the advance [decision] was signed".

This is precisely why the 1994 Committee opposed giving advance decisions greater legal force.

Regarding lasting powers of attorney (section 8ff), the 1994 Committee concluded that such a system "is vulnerable to the same problems as advance directives, and indeed to a greater degree."

I believe very strongly that this Bill is a vehicle by which the pro-euthanasia lobby are seeking to exploit the fears and vulnerability of patients and thereby introduce euthanasia by neglect through compulsory denial of life-sustaining treatment and care.

The fact that the Voluntary Euthanasia Society are welcoming the Bill ought to set alarm bells ringing.

The key principles and proposals of this Bill are so dangerous that it is unacceptable for the Government even to propose the Bill as public policy, let alone introduce it into Parliament.

I submit that the Government should scrap the Bill and examine closely how its policy development in the area of mental incapacity went so astray as to arrive at such unethical proposals.

August 2003

86. Memorandum from Dr Darach Corvin (MIB 791)

1. I am a medical practitioner of 32 years standing, having spent the past eight years in hospital practice and the last 24 years in full time general practice. Throughout all my years of practice I have dealt with chronic illness, terminal illness and death on an almost daily basis.

2. The withholding or withdrawal of fluids and food from an ill patient is a not uncommon event. It is invariably a decision made between relatives and medical staff concerning a terminally ill patient where the administration of food and fluids is either too distressing or dangerous for the patient, or where its administration would unnecessarily prolong a fading life. This is good medical practice and is in the patient's best interest. The words "ill" and "terminally ill" are precise and critical to the principal that guide this practice.

On a practical level, I have never come across a situation where relatives or staff decide to withhold or withdraw food and fluids from someone who is:

- (a) not ill;
- (b) not terminally ill with a hopeless prognosis;
- (c) likely to suffer distress as a result of withholding or withdrawing food and fluids.

The thought of withholding fluids and food from such an incapacitated patient with the deliberate intention to end life would horrify me and the vast majority of medical staff. To be fed and hydrated have always been accepted as much a part of humane nursing care as physical hygiene, comfort and the relief of suffering. Food and fluid are not medical therapy.

3. I would like to comment on legally binding “living wills”. If an unqualified and unaccountable attorney were to try and force me to bill my patient by withdrawing or withholding fluid and food, and if I thought that this was not in the patient’s best interest, I would simply refuse and risk the consequences. I cannot think of anything more likely to undermine and corrupt medical staff than the withholding of nutrition and where there is a medico-legal threat forcing them to act against their best judgements. These practices would totally undermine the work of the staff in the field of palliative care and greatly affect the patient-doctor relationship.

Anyone who has any knowledge of the medical profession is aware of how subtle pressures can degrade the practice of medicine at a very basic level. Patients are rightly worried when they feel that their doctor may not be acting in their best interests. This was very keenly felt at the time of GP fundholding in the 1990s and had a significant negative impact on the doctor-patient relationship.

- 4. I would ask you to bear these above thoughts in mind when you make your deliberations.

August 2003

87. Memorandum from Mencap (MIB 792)

OVERVIEW AND BACKGROUND

Mencap welcomes the publication of the draft Mental Incapacity Bill and is pleased to be able to respond to this consultation process. Mencap has been campaigning on the need for legislation in this area for more than a decade and hopes that the draft Bill becomes legislation during the next parliamentary session. We consulted widely with Mencap members and local staff with interest in this area to reach our recommendations. We will also be holding a national consultation day for people with a learning disability in early September. An analysis of this response will be shared with the Scrutiny Committee.

Mencap welcomes the key principles in the Bill, which we believe, will empower and support people with a learning disability to make their own decisions in day to day matters. The Bill will also clarify who has the legal right to take day to day welfare, healthcare or financial decisions on behalf of people who lack the capacity to make decisions independently.

However, Mencap does not feel that the Bill currently contains sufficient mechanisms to ensure that these principles are implemented in practice. Mencap would like to see mechanisms in the Bill to allow people to challenge decisions made on their behalf. This is why we are continuing to press for the inclusion of advocacy on the face of the Bill and for additional safeguards in relation to the General Authority.

Key principles in the draft Bill that Mencap welcomes include:

- Enabling people to make as many of their own choices as possible for as long as possible and to be supported to make their own decisions;
- Protecting people who cannot make their own decisions;
- Enabling supporters of people who cannot make decisions to take part in decision-making;
- Providing guidelines for professionals working with people who do not have sufficient capacity to make their own decisions.

KEY CONCERNS ABOUT THE DRAFT BILL

However, we have a number of concerns about the draft Bill. These are the following:

ADVOCACY—THE NEED FOR SUPPORTED DECISION-MAKING

There is a serious gap in the Bill. It does not state that advocacy is needed to support people to make as many of their decisions as possible. We are concerned that this gap may seriously affect some people with a learning disability.

Mencap believes that independent advocacy should have a key role in ensuring that:

- People are not wrongly assessed as incapable of making a particular decision;
- Once accurately assessed, people with impaired capacity are able to participate fully in decisions taken on their behalf, and are supported to develop their capacity to participate over time.

Although the Disabled Person's Act 1986 gives disabled people a qualified right to access independent advocacy, it has never been implemented. Valuing People, the learning disability White Paper, provides some funding to develop independent advocacy. This funding has been sufficient only to expand the geographical reach of advocacy organisations, not to ensure that all people with a learning disability can access an advocate. Evidence suggests that funding has been cut for some advocacy services.

THE GENERAL AUTHORITY TO ACT

Mencap acknowledges the need to empower supporters to take effective decisions on behalf of people with impaired capacity and to feel that they are protected by law. The GA serves this purpose well, and the restrictions set out in clause 7 should prevent the worst abuses of its power (the supporter cannot use or threaten to use force). However, we are concerned that there is no mechanism in the Bill whereby people with a learning disability can challenge decisions taken under the GA.

We are also concerned about the universal scope of the GA. Our understanding prior to the publication of the Bill, was that the GA would apply to informal day to day decisions made by unpaid supporters. However, the Bill makes it clear that professionals will also be able to operate under its authority, and the Bill makes no distinction between a decision made by a health professional based on best interests and a supporter making a decision in a person's best interests. Professionals should be bound by a professional code of conduct and they need to be subject to tighter restrictions.

In the draft Bill, there is also no limitation placed on the types of decision that can be taken under the GA, other than that in all the circumstances it is reasonable. It may therefore be that in certain situations, for instance following a car accident or if a person is about to be discharged from hospital, consent may be given for significant health or welfare decisions under the GA. However, important decisions such as where the person should live should not fall under the GA. Again, access to independent advocacy may provide an important independent check on the reasonableness or otherwise of a decision.

LASTING POWERS OF ATTORNEY (LPA)

Mencap supports the widening of the scope of attorneyship from purely financial affairs to additionally cover the full range of health and welfare decisions. This would enable supporters who are looking after severely disabled people to apply to become an appointed person that will look after that person's financial, welfare and medical interests.

However, we feel that tighter controls should be placed on those who can be appointed as donees of LPAs. At present, an individual who is bankrupt may not be appointed. We believe that this exclusion should be extended to those convicted of fraud or abuse of a previous LPA. The Guardianship Office, which is responsible for these applications, should also be linked with the Criminal Records Bureau to ensure that the person is not on the Vulnerable Adults List.

As with supporters operating under the GA, we are concerned that donees holding wide-ranging powers under an LPA should be fully informed of their rights and responsibilities. It will also be important that the Public Guardianship Office effectively monitors the operation of LPAs.

COURT APPOINTED DEPUTIES

Court Appointed Deputies will replace the current receivership system. As with LPAs, Deputies will be able to take decisions, only if so appointed, across the full range of financial, health and welfare issues. Deputies can be appointed to make decisions on one or more strand of decision-making. We are concerned that the Court of Protection should only appoint a Deputy when an independent assessment of capacity to take a particular decision has been made. Also, the appointment of a Deputy is a key stage when we believe a right to access independent advocacy should be triggered. Unlike our position on LPAs, we do not believe that Deputies should always be able to give consent to the withdrawal of treatment. Rather, we prefer a requirement for a single order of the Court of Protection where circumstances permit.

THE NEW BODIES CREATED UNDER THE BILL

Court of Protection

Mencap supports the principle of a unified Court of Protection with High Court status, and the provisions for it to have a regional presence. Court of Protection judges and staff will need to have detailed training to fully understand the impact of this new legislation. Other training includes disability awareness training and training on the range of illnesses that may cause a person to lack capacity. The provision for the Court to make single orders on important decisions is particularly welcome.

The Public Guardian

Mencap believes that the Public Guardian will have a vital role to play in the successful implementation of this Bill. The Public Guardianship Office must be sufficiently resourced to effectively monitor any abuse of the powers set out in the Bill. Aside from two specified criminal offences (clause 31—ill-treatment and neglect; clause 32—concealing or destroying an advance decision), the Bill does not clarify what, if any, sanctions will be available to the Public Guardian if an individual is found to be acting outside the spirit of the Bill.

Title of the Bill

Mencap is concerned about the title of this Bill which, we believe, has negative connotations. The Bill is more positive than its title. It is about capacity and the support available when person may not be able to make his/her decision. Its assumption is that you have capacity to make that certain decision unless others prove the contrary. Therefore, it should be mental capacity rather than mental incapacity. All the countries that have introduced similar legislation do not use that terminology. In Scotland, it is called, Adults with Incapacity Act 2000, in Southern Australia, the Guardianship and Administration Act 1993, and in Canada, the Substitute Decision Act and Advocacy Act of 1992.

OMISSIONS FROM THE BILL

- Adults at risk—the Bill does not cross-refer to regulations and guidance around vulnerable adults, for instance No Secrets. While this relationship may be best considered in guidance, it is important that the Bill does not create parallel structures and mechanisms to those already in place. Mencap also support specific recommendations in Who Decides for Public Law Protection for People At Risk including a duty on social services to investigate possible cases of neglect or abuse.
- Appointeeship—this is where a person can be given responsibility by the Department of Work and Pensions for handling someone's welfare benefits (local authorities can do the same with housing benefit) because the person is not thought to be capable of doing it themselves. Mencap believes that appointeeships should be brought within the scope of the Bill, not least because the person in question is likely to be even more vulnerable by virtue of being dependent upon benefits. Appointees should be bound by the same best interest principles as those operating as Deputies or donees of LPAs.

FUNDING

Mencap believes that the successful implementation of this Bill will depend largely on the resources attached to it. Aside from the need for independent advocacy outlined above, the Bill will create a substantial training need across a range of professional groups such as doctors, nurses and social care professionals. Funding is needed to ensure that its powers are used as intended. Funding is also needed to educate the public about the new rights and procedures to ensure that they have access to the right information.

The Government has positioned the Bill as part of a progressive agenda, enhancing the civil and human rights enjoyed by people who may have difficulty making or communicating decisions. To make this vision a reality, Mencap believes that the Government must attach sufficient resources to this legislation to ensure that those who come under its powers have access to independent advocacy.

August 2003

88. Memorandum from Malcolm Underwood (MIB 107)
1. LEGAL RESPONSIBILITY

The 1948 Universal Declaration of Human Rights states that "everyone has a right to recognition everywhere as a person before the law" (article 6) and that "everyone is entitled to all the rights and freedoms set forth in this declaration, without distinction of any kind" (Article 2). The idea that someone might, on account of a disability "have no best interests" is in opposition to both the phrasing and the spirit of that declaration. Yet this was an opinion voiced during the case of Tony Bland (1994), who eventually died of dehydration. The judgement in that case, by redefining the provision of food and fluids to a patient as "medical treatment", and making their withdrawal permissible, also cancelled a basic level of responsibility to human beings in his condition which had hitherto universally obtained.

2. PERSONAL RESPONSIBILITY

It is a valid principle that persons can bind themselves by their own decisions as regards the conduct of their lives. Decisions necessarily are of a different order when they concern the renunciation of life itself. The official adoption of Advance Decisions, whereby a subject's oral statement alone, evidenced later by one witness, could lead to the withdrawal of food and fluids from that subject after he or she had become unable to voice dissent, is a travesty of justice. Not only that, but a person rendered unable to dissent by illness contracted after they had made the Advance Decision is completely open to exploitation by others, at a time when what is needed is greater protection by society.

3. THE NEED FOR PROPER CARE, AND THE RESPONSIBILITY OF RECOGNISING IT

The consequences of a more open attitude can be made clear. The case of Marian Sallery shows how wrong some initial judgements can be. She was wrongly diagnosed as being in Persistent Vegetable State in 1983, continued to be sustained by nutrients at the wish of her parents, and was later found to have been in a state of non-communication but of perfect awareness, and lived in a Cheshire Home until 1994. This person had the benefit of better care, because the initial suggestion that the basics of life should be withdrawn was refused on her behalf. My own mother suffered two strokes while in an institution providing day and night care, and as a family we were able to continue visiting her, celebrating birthdays, and being present up to her death.

4. INTERPRETATIONS OF ADVANCE DECISIONS

My last point concerns the way in which the proposed legislation may be stretched. The "Making Decisions Alliance", a group of 30 voluntary sector organisations has welcomed the MIB, claiming that "although advance decisions are sometimes concerned with the refusal of life-sustaining procedures in the event of terminal illness, they have nothing to do with euthanasia or suicide". The provisions of the Bill, however, do not stipulate that the decisions would only apply in such cases. Rather, they could become operative simply as a result of mental incapacity. With supply or withdrawal of nutrients now defined in the UK as an aspect of medical treatment, it is clear that the effect of some Advance Decisions might be to end life by means of such withdrawal. The Americans are apparently more alive to this danger. In the majority of States which have approved Living Wills, the relevant legislation specifically excludes termination of life by those means. In fact, although this Bill claims to give greater individual responsibility and freedom, it is in fact paving the way for a culture of euthanasia: withdrawal of hydration and nutrition have to the best of my knowledge been espoused by the pro-euthanasia Hemlock Society.

August 2003

89. Memorandum from the Reverend Patrick Tansey (MIB 130)

DRAFT MENTAL INCAPACITY BILL

First, I should like to state my concern that this Bill, which has good points, is being discussed so rapidly and with a closure date for submissions being set for 1 September of this year. I should be most grateful to know why the haste, especially during the holiday period? I have only recently returned from mine!

For some time I have been following the issues dealt with in this Bill, especially, in my last parish, with the assistance of Dr Julian Lewis MP. In spite of numerous letters to the Lord Chancellor's Office, he was unable to receive any clear statement on matters related to Euthanasia by Omission, namely the withdrawal of food and fluid from mentally incapacitated patients with the purpose of ensuring death. As you will realise, this is totally separate from the question of the withdrawal of food and fluid if distress is being caused to the patient.

It is, therefore, essential that any proposed legislation include a clause making illegal the withdrawal of food and fluid with the purpose of causing death. Such a clause would not prevent the withdrawal of food and fluid in the case of distress, if clearly framed.

As one who has been a chaplain to a centre for learning disabilities for several years, I feel that definition of the patient's best interests in any legislation needs to be clear. My understanding is that the present wording is so vague in the area of medical criteria that the best interests of the vulnerable in relation to medical care are not adequately safeguarded.

There is also, I believe, a need for some clear appeal system in relation to Lasting Powers of Attorney, where a dispute concerning questionable medical treatment arises. This is one reason why this Bill deserves a more considered approach than it appears Government is giving it.

I recall Dr Lewis asking in one letter if, following a road accident, a doctor would be obliged, as the result of a "Living Will", not to give normally accepted medical help to an injured person in a serious condition. The question was not answered.

The whole legal status of "Living Wills" demands clear definition in any legislation, and a House of Lords Select Committee has warned of the use of Statute Law in this area. This area needs to be considered most carefully.

You will realise that I have grave concerns in relation to aspects of a Bill which could be of great value, but could also create a legal and moral nightmare for lawyers and medical personnel—to say nothing of family and friends of the incapacitated person!

August 2003

90. Memorandum from Mr Richard S Webb (MIB 138)

1. PERSONAL EXPERIENCE OF POWER OF ATTORNEY

1.1 For some six years, until our Mother died in 1974, my sister Elizabeth and I held Power of Attorney for Mother and Father. This worked very well—including the selling of securities to buy an annuity and all medical and welfare matters.

1.2 My sister Mary gave Power of Attorney to her three children. This worked well in every possible way. My sister Ruth has given Enduring Power of Attorney to the same three but no action has yet been needed.

1.3 My sister Elizabeth, who now suffers from Alzheimer's disease, has given EPA to her son Max. She is now incapable. A muddle with the solicitor left him on his own instead of including his wife Anna to work "jointly and severally". Max has (as I write) entered hospital with Angina for observation and possible surgery.

1.4 A friendly neighbour has had excellent experience as Attorney in an E.P.A. for an old lady with no near relatives.

1.5 My wife and I have both made EPA in favour of each other and our two children "jointly and severally". We are aged 77 and 80.

2. DRAFT MENTAL INCAPACITY BILL, (JUNE, 2003)

2.1 Those who have drafted this Bill have viewed the matter from all possible angles—a mammoth task. As far as I can tell most circumstances have been covered.

2.2 I have not been able to work out how the donor would continue to be supported if only a single donee is appointed in a Lasting Power of Attorney and he or she are unable to act for any reason. This may become a problem with my sister Elizabeth as I write. I have identified many Clauses and Sections that relate to this but I am not clear who would initiate action with the Public Guardian and/or the Court of Protection. Please make it clear for a layman like me as to what to do. It is probably clear already to those who drafted the Bill, (see this memorandum section 2.9).

2.3 In the same way if someone becomes mentally incapable with no LPA how could concerned family, friends or professional group recover the position and establish and register a LPA?

2.4 There should be no absolute assumption that a spouse should at once take charge of care arrangements for their partner. They may be about to have an acrimonious divorce. Medical and social workers should at least initially use their own judgement. Perhaps Clause 4 (1) and (3) (b) helps.

2.5 Checks and controls are well set out. However good will, patience, competence, time and available finances will always be necessary for donees and deputies. It seems important that no Agency is allowed to interfere with the activities of a donee or deputy unless they are very sure of their ground. I am aware that some terrible child abuse cases have been revealed too late to help the child—but parents have their children on their hands whether they like it or not. Carers, donees and deputies for a person lacking capability are effectively volunteers and heavy handed control would become known and make potential donors less inclined to impose on relatives and friends and also relatives and friends less inclined to become involved. A balance of benefit should be found. Clause 31 or notes of guidance should have a reference as to whom an initial complaint be made.

2.6 Clause 13, and others, appear to help to avoid technical breaches of the Bill (or Act) when committed in good faith to help the donor.

2.7 I trust that an interpretation of Clause 25(5) would not prevent my donee from ensuring that I have sufficient pain relief should it be necessary even if the side effect is terminal. Particularly I do not want to die of asphyxiation.

2.8 Under Schedule 1, Part 1, Clausel(l)(a), where will the necessary form be available? Please state.

2.9 The Bill, Schedules and Explanatory Notes are fine. Please will someone prepare and make available a simple introductory statement, like the enclosed copy of the first sheet of an Enduring Power of Attorney, as an introduction for anyone thinking of executing a Lasting Power of Attorney and a potential donee or deputy. There should also be prepared a summary of how a LPA may be prepared, registered and used giving examples of financial and property deals, general affairs, administration, medical and welfare matters over which the donee or deputy may have control—both before and after the donor ‘P’ becomes mentally incapable. Note Annex A, Option 4, Clause 14. This document could be the equivalent of the Highway Code which states on the back cover that it is not a substitute for the Road Traffic Act, 1988 or other legislation but “—as tending to establish or negative any liability which is in question—”.

2.10 As more than one copy of a LPA will be needed please state how Certified Copies may be obtained. I hold 6 copies of my EPA.

2.11 Annex A is very interesting and makes a clear case for introducing LPA’s. But do not under estimate the value of EPA’s in the meanwhile if properly and tactfully used.

2.12 Costs may be a barrier for some people either for financial reasons, in which case the DSS or Charities might help—as is done now to encourage people to make Wills—or prejudice.

2.13 In time I hope that under Clause 3 of Schedule 1 it will become acceptable for a donee to be called an attorney—a far more dignified and explicit name.

3. CONCLUSIONS

3.1 The Draft Mental Incapacity Bill is well thought out and should be enacted by Parliament with the minimum of delay. If some or all my comments could be dealt with, say, in a Highway Code type document this would be excellent.

3.2 To hold a LPA seems to be almost as important as a Will—an insurance policy. There will have to be a Awareness Campaign since pathetically few people hold EPA’S. at present. Government, the DSS, Social Services and Charities could work together. Individuals could be given simple sheets, like the front of the E.P.A., to pass to friends and relations. Inertia needs to be overcome.

August 2003

91. Memorandum from Dr Dermot Lynch (MIB 173)

I am very concerned about some of the clauses in this draft.

1. They appear to allow the withdrawal of tube supplied food and fluid for the purpose of ending life when someone judges that death best serves the interest of the person.

2. This may be decided by someone who could have an interest in the death of the individual but who claims to have knowledge of an advance decision verbally expressed. Even a written directive will have been made in different circumstances and may be is a poor reflection of present opinion which cannot be expressed.

3. Doctors will be expected to take the action of tube removal or withholding thus abrogating their responsibility to respect life, to heal where possible, to ease suffering and to do no harm. The fact that the profession has already abandoned this principal in regard to abortion is no reason to extend the abandonment.

4. The Court of Protection will be altered in a manner, which will reduce the protection provided to the most vulnerable.

The State can of course alter the Law of the land but cannot alter the morality! Should the State decide to alter the laws in the manner of the objectional clauses it should be honest and accept that:

1. They are legalising killing by starvation and dehydration.

2. Doctors are being required to do this because of humane reasons but death by starvation is slow and distressing and a subject who cannot communicate is not necessarily unfeeling. Those most skilled in humane killing are abattoir staff!!

3. The State is abrogating its duty to protect the most vulnerable members of society.

August 2003

92. Memorandum from Depression Alliance Cymru (MIB 188)

I am writing to give a cautious welcome to the Draft Mental Incapacity Bill 2003, which, if implemented will do much to meet the concerns raised by Depression Alliance Cymru during the debate around the Draft Mental Health Bill last year.

1. The Draft Mental Incapacity Bill 2003 sets out conditions for mental incapacity which would mean that almost all people affected by depression would be deemed to have capacity. Furthermore, by placing the burden of evidence on the authorities to prove that a person lacks capacity, it almost guarantees that a person affected by depression would not be subject to detention and/or compulsory treatment.

2. I do have a number of concerns with the Draft Mental Incapacity Bill 2003:

SUBSTANTIAL RISK

3. First, there are two clauses—7(1)(c) and 10(2)(b)—concerned with the risk of harm to a person lacking, or thought to lack capacity. In these clauses, the term “substantial risk” is used, as it was in the Draft Mental Health Bill 2002. During the consultation it emerged that “substantial risk” would be taken by the courts to mean only “that the risk has substance”. Using this definition, there is a substantial risk that any person with depression will take their life or carry out serious self-harm, just as there is a substantial risk that a young male who consumes alcohol in a public place will commit homicide. The use of the term “substantial risk” undermines the rights of those who have mental capacity—such as almost all of those with depression—who are clearly intended to be protected by this Act. Another, more precise term—such as “apparent and imminent danger” or “quantifiable and imminent danger” would be more appropriate to providing protection to those genuinely lacking capacity while safeguarding the rights of the majority.

ADVANCED DECISIONS TO REFUSE TREATMENT

4. The sections giving legal force to advance decisions are to be welcomed. This is particularly important at a time when Government values the self-help and self-management of expert patients who experience episodes of mental ill health which may, on occasion, result in their becoming mentally incapacitated. These proposals at least allow that expert patients know which treatments and therapies do not work for them.

5. Unfortunately, the proposed new right is entirely negative. It confers a right to refuse treatment, but has no corresponding right to request treatments known to the patient to be effective. An additional clause requiring practitioners to take account of advanced statements on preferred treatments would be a welcome enhancement to the Draft Mental Incapacity Bill 2003.

6. I am concerned with the degree of precision over treatment apparently required of the incapacitated person in 23(4)(a)-(c). It is important that the broad thrust of the proposed legislation is not lost in the detail. Common sense tells us that a person who refuses, for example, ECT also refuses ECT in combination with cognitive behavioural therapy. However, a practitioner might be able to stretch clause 23(4)(a) to suggest that this would invalidate the advanced statement. Much of this will no doubt be clarified in the proposed codes of practice. Nevertheless, I would urge that 23(4)(a) be amended to read, “that treatment is not and does not include the treatment specified in the advance decision.”

7. I would also draw your attention to 25(2) which indemnifies practitioners from carrying out or continuing treatment refused in an advance decision. This clause is far too passive, since a failure to ask is all that is required to avoid liability. It would not be unreasonable to ask that a practitioner take reasonable steps to ascertain whether an advance decision exists prior to embarking on a course of treatment. I would suggest that 25(2) should read:

8. “A person does not incur liability for carrying out or continuing the treatment if, at the time—

- (a) he has taken reasonable steps to find out, and
- (b) he has no reasonable grounds for believing, that an advance decision exists which may be valid and applicable to the treatment.”

9. Amended in this way, the clause would require that a practitioner at least ask next-of-kin whether an advance decision exists. Furthermore, if an advance decision exists, the substitution of the word “may” for “is” would oblige the practitioner to seek advice before rejecting the terms of the advance decision.

CRIMINAL OFFENCES—REMEDIES

10. The Draft Mental Incapacity Bill 2003 creates two new offences—ill-treatment and/or neglect of an incapacitated person by the person(s) charged with their care, and concealing or destroying an advance decision to refuse treatment. These offences are to be welcomed. However, the proposed remedies do not seem proportionate to the seriousness of the offence.

11. Bearing in mind that we are talking about offences committed against—by legal definition—the most vulnerable people in our society, two years imprisonment and/or £2,000 fine is positively lenient. The offences concern matters more akin to serious assault than to, for example, shoplifting. As such, one would expect a maximum term of, perhaps, 10 years imprisonment to be more fitting.

12. I trust that you will take these matters into account in your committee's deliberations.

August 2003

93. Memorandum from Marie Columb (MIB 198)

1. As a registered nurse in a stroke unit I am involved with decisions to treat or whether prolonging life is too burdensome, regularly. It is very obvious that as a patient becomes more dependent their personal wishes become more intense and then blurred as they see themselves as being a burden on their loved ones. I have seen relatives swayed by the patient themselves or by other relatives into believing they want to be left to die and putting great pressure on doctors who believe there is a very sustainable life to be treated here. Quite apart from the fact that these relatives usually have no idea what is involved when you allow a patient to die from neglect when they are not dying I feel as a nurse I am morally bound to protect and sustain life. We live in a society prepared to do anything to get what they want, a society who is used to thinking of disabled people as being less than human or as second class citizens. I have seen patients in my care refusing all treatment, unable to face life disabled and going through an agonising death despite all our efforts. A death from starvation and following a "not too serious" stroke but their choice has been respected and their wishes upheld. There was no need for an advanced directive.

2. In our hospital the view is that diet and fluids are a basic human right and are not treatment be it by ANH (Artificial nutrition and hydration) or ordinary nutrition and hydration.

I feel that Florence Nightingale was correct. Her motto was simply "Do no harm".

3. Often a decision to treat can be complex and one informed conscience can differ from another as we have seen on the news as pathologist experts have come to such differing conclusions even under oath in court on many occasions. It is now generally agreed that the decisions made from the collective conscience of "the team" (of doctors, nurses, physiotherapists, occupational therapists and social workers) is medically and ethically correct and bound to be less subject to the unreasonable pressure a relative or indeed the patient themselves may feel.

4. Consultants are always looking for simple ways to be able to come to the right decision in all cases (without damaging the traditional paternal role they have held in the past. Unfortunately many patients or their relatives have lost the trust they used to have in doctors. This bill would further damage that trust.

5. The public seem to feel they must make their Advance Directive now while they are healthy because it will be expected of them to make these huge decisions about their treatment when they are at their most vulnerable. When they are probably still feeling very traumatised and are certain to be the least informed about what is ahead of them or will be available and the type of life they will need to adapt to. When in fact this is not true and the treatment of these people would be severely hampered if the doctors were prevented from treating them because of a legally binding Advanced Directive that was written many years before.

6. It is common knowledge that your views change from day to day and when you are actually in a life and death situation your views change dramatically from what they may have been when you first wrote the directive. Our aim is to always inform our patients as much as possible about their stroke with videos, tapes and leaflets when they come in first. Having seen the information you can see the change in their attitude and the realisation that there is so much more they don't know. They realise they need to rely on the professionals and they relax and are prepared to wait and see what real damage is left after 6–8 weeks. Each stroke is different. Legally binding advanced directives would only inhibit their care.

August 2003

94. Memorandum from Dr Charles O'Donnell (MIB 320)

Thank you for offering me the opportunity to express my views regarding the aforementioned Act of Parliament.

As a doctor working in critical care I am frequently involved in end of life decision-making. This includes withdrawing artificial ventilation, terminating attempts at cardio-pulmonary resuscitation and refusing entry into Intensive Care. The proposal to offer Continuing Power of Attorney to somebody who is not

medically qualified and dealing with the particular case in hand concerns me greatly. Such a proxy decision maker may be influenced in his or her decision making process by factors that have little or no bearing on the overall best interests of the patient.

One commonly meets relatives who are overwhelmed by the complexity and perceived burden of medical therapies who may therefore if given the casting vote opt for treatment withdrawal based (albeit in good faith) on false perceptions of the overall benefit-burden ratio.

Sadly what is even more frightening about the Lasting Power of Attorney proposal is that it naively assumes that the attorney is incorruptible! If an individual may benefit financially from a patient's death the true best interests of the patient are compromised

It is vital that in any just society the law should protect the most vulnerable as effectively as possible. A senior clinician taking regard of the valued opinions of other healthcare professionals and the relatives of the incapacitated person who is ultimately accountable to the courts is the best way to achieve this goal.

Undoubtedly, patient autonomy is one of the important factors to be taken into the equation when making end of life decisions. It is a paradox that the advocates of this Act of Parliament see it as a means to protect autonomy whilst in fact it runs the serious risk of threatening this right for the most vulnerable members of our society. If the more privileged members of society, I guess like you and I, have to tolerate a slightly perceived or indeed actual diminution of our right to autonomy in order to protect the common good then that is to my mind true justice.

The common good is that situation that ensures the rights of the most vulnerable even at the expense of the more fortunate should be the guiding maxim of any law relating to the incapacitated.

Once again thank you for the opportunity to express my view. I hope the draft will be amended accordingly.

August 2003

95. Memorandum from the Society for the Protection of Unborn Children, Kensington and Chelsea Branch (MIB 333)

1. The 123 lay, and 35 clergy, SPUC members in Kensington and Chelsea are very concerned about the threat of legalised euthanasia by omission today. Thirty of us went to the House of Commons in April 2000 to ask our MP Michael Portillo to support Mrs Ann Winterton's "*Medical Treatment (Prevention of euthanasia)*" Bill. I submitted some four A4 pages upon the consultation paper "*Making Decisions*" to the Lord Chancellor's department, in July 2002. SPUC members in Kensington and Chelsea include the founder of the group "Nurses opposed to euthanasia", whose statement of aims I enclose, the Secretary of "Against Legalised Euthanasia Research and Teaching", a former borough councillor, and a member of the "Association of Lawyers for the Defence of the Unborn".

2. The pressure to allow patients to be killed in hospitals owes much to 6,000,000 babies killed by legal abortion since 1967. There are fewer people to pay for and undertake the care of the elderly and ill. I believe the evil of abortion should not lead to the legalising of euthanasia.

3. Alas, euthanasia by omission has happened by court order: several patients have died thus in England and Scotland since Tony Bland was starved to death in 1993, and every incapacitated patient is threatened. I disbelieve the Government's stated opposition to euthanasia, referring only to active euthanasia. To kill a patient by starvation and dehydration is euthanasia, and I submit this is the object of certain proposals in the Government's draft Mental Incapacity Bill. I helped care for my great-aunt who suffered mental incapacity, and for my grandmother who suffered recurring depression, and in the light of this experience I oppose legalising euthanasia, absolutely. While depressed, my grandmother was inconsolably miserable, and she told me how she sometimes thought of suicide. Notwithstanding, we cared for her until she died naturally. To have starved her to death would have been a terrible denial of a family's duty of care. It is always, everywhere and without exception wrong to kill patients, however emotionally hurtful their condition, for to do so means they are deemed to have only a qualified right to life.

4. Of course the draft Mental Incapacity Bill follows years of consideration. The Law Commission began six years of consultation upon mental incapacity in 1989, and the Government's Green Paper of 1997 "*Who Decides*", and its policy statement of 1999 "*Making Decisions*" are important. I suggest, the intensive pressure to legalise euthanasia from certain quarters has influenced this Bill. Lord Filkin, Minister of State for Constitutional Affairs, launched the Bill stating it would create a "framework" for the mentally incapacitated, enabling people to "plan ahead for a possible incapacity" by creating a "Lasting Power of

Attorney". I ask you to consider the serious danger that, in order to minimise the cost of incapacitated people—or even to benefit from their estate—Attorneys may order doctors to starve them. My great-aunt's incapacity was excruciating—she said the same thing up to 50 times over, was sometimes incontinent, and spoke of her dead brother and sisters as if alive. She had no such Attorney as the Government proposes, and her family and I cared for her until natural death.

5. The draft Mental Incapacity Bill defines patients' best interests in a seriously deficient way. In 2000, Ms Yvette Cooper, then Minister for Health, clearly implied continued life is not always beneficial to patients, in a reply to my MP Michael Portillo writing on my behalf. She considered that Mrs Winterton's "Medical Treatment (Prevention of euthanasia)" Bill 2000 "... might require artificial nutrition and hydration to be continued even when no longer of benefit to the patient" (my emphasis). The Bill pursues this idea, by considering best interests as being defined by the ascertainable "wishes and feelings" of the incapacitated individual. The Bill omits any reference to such basic principles as sustaining life and promoting health, which are acknowledged by doctors as the objects they pursue, and endorsed in legal judgements as among best interests. I submit patients' best interests must include receiving food and drink—by tube, or fork whilst capable of digestion, and this redefinition aims to legalise killing people, on grounds like "well, he wouldn't want to go on living like this" (notably, in the case of Tony Bland: he was killed by dehydration without ever having indicated his wishes before or after he was injured). My grandmother thought of suicide while depressed, and my great-aunt suffered great distress while incapacitated, but I and my family did not starve them.

6. I submit that the draft Mental Incapacity Bill will undermine the foundations of medical morals, by giving statutory force to advance decisions to refuse treatment, and treating food and drink as medical treatment. It is ludicrous that I, or any human being, should need a doctor's order to eat and drink, yet the bill could deliver me to starvation if incapacitated, by considering tube feeding as medical treatment. I draw to your attention aim no. 4 of the group "Nurses opposed to euthanasia": "To challenge the increasingly accepted belief that nutrition and hydration constitute medical treatment, considering assisted nutrition, in almost every case as a basic necessity of care, when required, appropriate and possible". I believe medicine should follow the precept "thou shalt not kill, but needs not strive officiously to keep alive", and the Bill represents an appalling attack on this principle. It breaks the Government's undertaking not to legislate on advance decisions (Lord Hunt of Kings Heath, House of Lords website, 3 February 2000), and will make it impossible for anyone, once incapable, to revoke a living will they made in the past. In this context, we should remember that individuals have recovered from so-called Persistent Vegetative State—and resumed active life!—and incorrect diagnoses have been made, such as the case of Marian Sallery. I recall neither my grandmother nor my great-aunt made an advance directive—and a very worrying point in leaflet 6 of the Government's consultation paper "*Making Decisions*" was its emphasis on patient autonomy to the exclusion of health and life, leaving no room to continue food and drink and implying that a patient without a living will should be starved to death.

7. Finally, the draft Mental Incapacity Bill transfers the High Court's inherent power over "serious healthcare cases" to the Court of Protection. Its proposed authority over all areas of decision-making would include power to cut off food and drink from incapacitated people, denying the name "Protection". By the way, my incapacitated great-aunt was married to a High Court judge, Sir Roualeyn Cumming-Bruce, and he cared for her unstintingly.

8. I submit: the Government's conduct is extremely unhelpful and only likely to bring it into disrepute, in setting a deadline of Monday 1 September for responses to the draft Mental Incapacity Bill. The Government has shown its disregard for public debate and for human life before. In December 2000, a statutory instrument allowing so-called therapeutic cloning that is, creating human beings to cannibalise them for research—was rushed through Parliament. The then Leader of the House of Commons, Margaret Beckett had promised long-term debate upon human cloning, in November 2000, just as Lord Hunt undertook not to legislate on advance decisions in February 2000. The Government now proposes to Parliament a bill allowing people to be killed in hospitals, setting a deadline for submissions far too short to allow many individuals and groups deeply concerned by this issue, to respond. This conduct by Tony Blair's Government, so contemptuous of due Parliamentary procedure, is reminiscent of Margaret Thatcher's hubris after her third election victory.

9. Therefore, I ask you to safeguard the elderly and ill by resisting the proposals in the draft Mental Incapacity Bill.

I copy this letter to my MP Mr Portillo, who wrote in a letter to me in May 2001, concerning his voting intentions in the present Parliament: "I am not in favour of euthanasia. People who are old or ill have the right to live free from fear, and confident that they will be treated ethically."

August 2003

Nurses opposed to Euthanasia

“FIRST DO NO HARM”⁹

GROUP OBJECTIVES:

1. To be prepared to protect patients from people/practices which are aimed at killing them.
2. To maintain the historical nursing duty of care and respect for people, who may or may not be able to speak for themselves.
3. To offer a network of support and encouragement to nurses concerned about the threat to life of patients in their care/work environments.
4. To challenge the increasingly accepted belief that nutrition and hydration constitute medical treatment, considering assisted nutrition, in almost every case as a basic necessity of care, when required, appropriate and possible.
5. To continue the tradition and maintain the right of nurses to act as the patient's advocate with support from the profession.
6. To achieve an addition to the Nursing Code of Professional Conduct¹⁰ to protect nurses from being forced or required to carry out any clinical orders/decisions which compromise the nurse's duty of care, patient safety and physical and/or mental well-being.
7. To work against the threat of legalised euthanasia and promote humane, compassionate care alternatives.
8. To raise awareness of the UKCC Nursing Code of Professional Conduct in relation to respect for people's rights in relation to ethical/religious beliefs.

96. Memorandum from Alison Davis (MIB 337)

SUMMARY

This is a personal submission. I have several severe disabilities and 18 years ago I wanted to die, a settled wish that lasted over 10 years. Had the legally binding Advance Decisions described in the MIB been in place then, I would not now be alive. I have Power of Attorney for my elderly mother who has senile dementia.

The submission highlights grave dangers in the draft Mental Incapacity Bill (MIB).

Section 2 highlights dangers associated with the MIB's definition of “best interests” as being the ascertainable past and present “wishes and feelings” of the incapacitated person. I suggest that this is highly dangerous and that the incapacitated person's clinical best interests should be the criteria which determine their treatment. Several examples are given of cases in which an apparently incapacitated person was assumed to be “better off dead.”

Section 3 notes the dangers of assuming that Advance Decisions are legally binding. It also questions the received wisdom that assisted food and fluids are “medical treatment” which can legitimately be withheld or withdrawn. This section notes that many people make decisions when they are ill which are not consistent with their Advance Decision. Several examples are given which highlight the dangers of such Decisions being legally binding.

Section 4 mentions the problems of allowing Lasting Powers of Attorney to make life and death decisions on behalf of incapacitated people. It notes that a change is needed to ensure that anyone who acts on behalf of an incapacitated person with the purpose, or a purpose, of hastening their death should be guilty of a criminal offence.

Section 5 highlights the contradiction in terms of naming as the “Court of Protection” a body one of whose chief functions should be to underwrite decisions to withhold or withdraw food and fluids with the aim of causing or hastening the death of an incapacitated person.

Section 6 notes that the Government has claimed to be “opposed to euthanasia” but shows that in supporting the MIB, it is also supporting the killing by neglect of the most vulnerable people, notwithstanding its own very narrow definition of “euthanasia”.

⁹ Florence Nightingale: *Notes on Nursing (Hospitals)* (1863), of The Hippocratic Oath.

¹⁰ United Kingdom Central Council for Nursing, Midwifery and Health Visiting, *Code of professional Conduct*.

Section 7 highlights some of the unsatisfactory terminology used in the MIB, for example the claim that food and fluids delivered by tube or PEG are “artificial,” rather than assisted, nutrition and hydration.

Section 8 explains why I would not now be alive had the terms of the MIB been in place 18 years ago.

Section 9 is a brief appeal to the Government to act to protect the true, clinical, best interests of the most vulnerable people. If it fails to do so, it will be guilty of killing in the name of “protection”—a contradiction in terms and the most serious derogation of its duty to care for those who cannot speak for themselves.

1. INTRODUCTION

I write as a member of the public who has a particular interest in the issue of decision making for people with mental incapacity. I have spina bifida, emphysema and osteoporosis and am a full-time wheelchair user. I have particular concerns about legally binding “Advance Decisions” since, had these been available 18 years ago, I would not now be writing these comments (see section 8.1).

My mother has senile dementia and does not have the mental capacity to make medical decisions for herself. I have Power of Attorney for her.

I have read the Draft Mental Incapacity Bill (MIB), and have grave concerns about some of its contents.

2. “BEST INTERESTS” AND AUTONOMY

2.1 “Best interests” are generally understood, as is reflected in case law¹¹, to include basic factors such as preserving life, maintaining or restoring health and minimising suffering. It is extremely worrying that the Draft Bill makes no mention of clinical “best interests” nor of the patient’s interest in not being deliberately killed, for example by having food and fluids withdrawn. Rather in the draft MIB “best interests” is defined as the ascertainable past and present “wishes and feelings” of the incapacitated person.

2.2 This is problematic for many reasons, not least in the case of depressed people who are suicidal. They “wish” to die and “feel” that death is in their best interests, but any doctor worthy of his or her profession would nevertheless overrule these wishes and feelings and institute treatment to save and/or sustain the life of such a patient. Similarly even if a patient strongly “feels” that a particular drug would benefit him and “wishes” it to be prescribed, a doctor should prescribe it only if he feels it will actually benefit the patient’s medical condition. Relying on “wishes and feelings” suggests that life is not a basic good unless the individual recognises it as such.

2.3 It is unclear how the “best interests” of people in Persistent Non-Responsive State (generally known as Persistent Vegetative State or PVS) would be served, if “wishes and feelings” are the only criteria for deciding who should die. Tony Bland, who was killed by withdrawal of his food and fluids in 1993 had never made his “wishes and feelings” clear on what he would want were he to become incapacitated. He was killed because other people “felt” that death was in his best interests and “wished” him to die.

2.4 Lord Mustill, a member of the appellate committee of the House of Lords which decided the Tony Bland case and a member of the 1993–94 House of Lords Select Committee on Medical Ethics proposed the highly objectionable view that Tony Bland had no best interests because he was profoundly disabled.¹² If a person has “no best interests” there would seem to be no justification for not killing him.

2.5 There have been many cases of people being wrongly diagnosed as being in PVS for whom withholding or withdrawing food and fluids has been considered in their “best interests.” One such case was that of Marian Sallery.

Marian Sallery was paralysed after a stroke in 1983 when she was 36 years old. Doctors told her parents that she was in PVS and would always be “a cabbage.” They discussed withdrawing Marian’s food and fluids in her presence. Her parents refused. Marian was transferred to the Royal Hospital for Neurodisability in Putney in 1990, and subsequently to a Leonard Cheshire Home, where she lived happily until her early death in 1994.

A post-mortem revealed that Marian had never been in PVS. Instead she had Locked-In syndrome, a condition in which the person cannot move or communicate but remains fully conscious and aware. Marian’s mother said the doctors “stood by her hospital bed and told us we should live our lives and accept that she was dead. She would have heard everything.”¹³

It is interesting to note that the doctors stated that Marian was “already dead” before the planned withdrawal of food and fluids, suggesting that living with disability is a form of “living death.” Disabled people need protection from the harm of being assumed to be “as good as dead.”

¹¹ Re F (Mental Patient; Sterilisation) [1990] 2 AC1, 78.

¹² Airedale NHS Trust v Bland [1993] AC 789.

¹³ “Coma blunder ends in horror” by Zoe Brennan *The Sunday Times* 21 February 1999.

Similarly Catherine Roberts, who is now 31 years old, had her food withdrawn after she had been in a coma for more than two months in 1992. She was expected to die within 48 hours, but eight weeks later she was still alive. Doctors decided to remove her tracheostomy tube, but the day before they planned to do this, Catherine responded to her mother's voice by blinking, sticking out her tongue and mouthing "I love you."

Six years later Catherine Roberts uses a wheelchair and is responding well. She accepted a £100,000 out of court settlement from the Royal Bournemouth and Christchurch Hospital Trust after issuing a writ alleging negligence in failing to make a proper diagnosis and provide appropriate care.¹⁴

Had the terms of the draft MIB been in place earlier, both Marian Sallery and Catherine Roberts would probably have been assumed to have "no best interests" like Tony Bland. Their cases show the appalling consequences of assuming that it is in the "best interests" of any patient to be starved to death.

2.6 In such situations the draft MIB suggests that Advance Statements should be used or, if no such statement has been made, that carers should be consulted about the patient's "past and present wishes and feelings and the factors he would consider if he were able to do so." There is no objection to carers and relatives commenting on how best to ascertain the clinical interests of a patient, but it is highly dangerous to put such people in the position of making judgements based on subjective assessments of what the patient "would have wanted" which may more accurately reflect their own interests.

2.7 None of the foregoing should be taken as implying that doctors should be required to provide straightforwardly futile or disproportionately burdensome treatment or to prolong life at all costs. It is clear that if a patient is irremediably dying s/he needs palliative care rather than treatment aimed at cure. Indeed, it is part of truly acting in the patient's best interests that the probable burdens of treatment options are addressed and inappropriate treatments either not initiated or withdrawn. Nevertheless, it is never right that a doctor's actions have the purpose, or a purpose, of causing or hastening the death of a patient. Being deliberately killed is never in a patient's "best interests."

3. THE ROLE OF ADVANCE DECISIONS IN DECISION MAKING

3.1 The Government has repeatedly stated that it will not make Advance Decisions legally binding, following the recommendation of the House of Lords Select Committee that Advance Decisions not be given greater legal force because this would risk "depriving patients of the benefit of the doctor's professional expertise and of new treatments and procedures which may have become available since the Advance Decision was signed."¹⁵

3.2 However, the MIB suggests that Advance Decisions are legally binding. This follows on from the leaflets produced by the Lord Chancellor's Department as part of the Consultation Paper Making Decisions: Helping People who have Difficulty Deciding for Themselves, which state that:

"So long as the advance statement is clear and is applicable in the particular circumstances in which treatment is proposed, health care professionals are bound by your earlier decision, even if they or your relatives or carers disagree with it (Re T (Adult: Refusal of Treatment) [1992] WLR 782)"¹⁶

3.3 The truth is that it has not actually been satisfactorily established that Advance Decisions are legally binding. The suggestion that they are binding appears to rest on three cases which are regularly cited in this regard. I assert that this claimed "proof" that such Decisions are legally binding is faulty for the following reasons:

- (a) *Airedale NHS Trust v Anthony Bland*. Anthony Bland was in a Persistent Non-Responsive State and died of starvation and dehydration after successive Court rulings approved his doctor's wish to withdraw his nutrition and hydration. The Court admitted that he had at no time given "any indication of his wishes" and by the time the decision was made, was completely unable to do so.¹⁷
- (b) *Re T*. This case was of a Jehovah's Witness who refused a blood transfusion. The aim of the refusal was not deliberately to end the patient's life, but was made because of religious beliefs concerning blood transfusions. The refusal of a transfusion did not involve a general refusal of treatment made in advance of the time when the patient was subject to the relevant condition.¹⁸
- (c) *Re C*. In this case the Court decided that the patient, who had schizophrenia, was nevertheless competent to refuse amputation of his leg, which was gangrenous. This Court ruling was binding on the doctors concerned, but the patient could have changed his mind at any time, and he knew the consequences of refusing the amputation. Again, this decision was not made in order deliberately to hasten death and, like *Re T*, this was not a case of a general refusal of treatment made in advance of the time when the patient was subject to the actual condition for which he refused treatment.¹⁹

¹⁴ "The coma girl who refused to die" by Sean O'Neill. *The Daily Telegraph* 11 June 1998.

¹⁵ Report of the House of Lords Select Committee on Medical Ethics 1994 (Session 1993-94, HL 21-1).

¹⁶ Making Decisions: Leaflet 4 "A Guide for Legal Professionals" 1992.

¹⁷ *Airedale NHS Trust v Anthony Bland* [1993] AC 789.

¹⁸ *Re: T (Adult: Refusal of Treatment)* [1992] WLR 782.

¹⁹ *Re: C (Adult Refusal of Treatment)* [1994] WLR 290.

3.4 These cases serve to illustrate that doctors are not, in fact, forced to act upon an Advance Decision. Additionally Mr Justice Hughes, in a ruling in 2001, indicated several provisos which must be present before Advance Decisions should be taken as legally binding, suggesting that if any one of them were not in place, the Decision would not be binding.²⁰ It is extremely worrying that the draft MIB would radically change this situation. Under its terms, any validly made out Advance Decision would be a binding legal instrument regardless of how old it was, how ill-informed the person making it, how hypothetical the condition or how much it anticipated the facts.

3.5 Since the Bland and Law Hospital judgements,^{21 22} food and fluids delivered by tube or PEG (Percutaneous Endoscopic Gastrostomy) have been considered “medical treatment” which can be withdrawn. Thus a doctor can withdraw or withhold them citing “medical grounds.” The draft MIB would allow “Advance Refusals” of “treatment” including food and fluids. I suggest that food and fluids, however delivered, are not “medical treatment” but basic nursing care, which should be provided unless the individual is close to death, and food and fluids would be unduly burdensome to him or her.

3.6 Doctors should strive to act in the clinical best interests of their patients. Doctors regularly resuscitate suicidal patients, even if there is a clearly written suicide note showing that the patient intended their actions to cause death. Similar judgments need to be made in the case of Advance Decisions with a clear suicidal intent in the event of the person becoming mentally incapacitated.

3.7 In the case of a patient who cannot make a current decision, the same duty of acting in his or her clinical best interests holds for the doctor. Deliberately causing or hastening the patient’s death should never be part of ethical medicine.

3.8 One problem in taking into account an Advance Decision refusing life saving or life-prolonging treatment is that by the time the decision is being taken by others, the person will almost certainly be incapable of indicating any change of mind. What one thinks one would want in a completely hypothetical situation, never before experienced, is not necessarily what one will want if that situation actually arises. This is particularly true of disabling conditions. Able bodied people, including some doctors, frequently have a very negative attitude towards living with disability, but once they actually experience it, their attitude is likely to become much more positive.²³

3.9 It has been shown that people often make decisions when they are ill that are not consistent with their Advance Decision. It has been found that

Approximately $\frac{1}{3}$ of patients changed their preferences in the face of actual illness, usually in favour of treatments rejected in advance.²⁴

The same study found that proxy decisions did not always agree with previously stated preferences. However, they erred in the same direction as those of ill and disabled people—towards treatment rather than against it. Treating Advance Decisions as legally binding means that there is no possibility of a change of mind, because the person would have been pushed into a death they might well no longer want.

3.10 Under the draft MIB, revocation of the Advance Decision requires “capacity” otherwise the Decision is valid and binding (note the case of Mrs Majorie Nighbert in section 4.2 and 4.3) While the draft MIB states that the Decision is not valid if the patient does “anything else clearly inconsistent with the advance decision remaining his fixed decision” this is less than helpful because the inconsistent act will only count if the person has “capacity” (see again the case of Mrs Nighbert). There is a grave problem as to who would give evidence to an “inconsistent act.” If it is to be the Lasting Power of Attorney, there is a danger that s/he would have an interest in the incapacitated person’s early death.

3.11 This sort of danger has been highlighted by Baroness Ilora Finlay, a Hospice doctor. She has spoken about a patient of hers, a lady aged 59, who was very ill. Her family seemed to be very concerned about her pain, and constantly asked for her diamorphine to be increased. However, the Hospice staff were not convinced that her pain was really that severe, and the patient herself declined increasing doses of diamorphine.

The lady’s 60th birthday passed with minimal celebration, after which the family visited her very little. She became very depressed, and finally told a night nurse that on her 60th birthday, her fixed-term life insurance policy expired, so the family would not now inherit the amount they had expected had she died. They had wanted her drugs increased, ultimately, so that they could inherit her money.²⁵

²⁰ Re: AK [2001] FLR 134 E-G.

²¹ Airedale NHS Trust v Bland Ibid.

²² “Judge says coma woman should be allowed to die” by Gillian Bowditch, Scotland Correspondent. *The Times* 25 April 1996. Lord Cameron of Lochbroom said that Law Hospital in Strathclyde could stop “artificially feeding” Mrs. Janet Johnston, a 53 year old woman who was in PVS for four years. Her food and fluids were withdrawn and she died 15 days later in May 1996. It was Scotland’s first such case.

²³ B.P. Gardner, F. Theocleous, J.W.H. Watt & K.R. Krishnan. Ventilation or dignified death for patients with high tetraplegia *BMJ* 1985, 291: 1620–22.

²⁴ Melinda Lee. Do patients’ treatment decisions match advance statements of their preferences? *Journal of Clinical Ethics* 09:03 (Fall 1998) 258–262.

²⁵ Debate on Mental Health in the House of Lords. Hansard 18 December 2002. Column 766.

3.12 The House of Lords Select Committee, which reported in 1994, opposed giving Advance Decisions greater legal force, saying this would risk “depriving patients of the benefit of the doctor’s professional expertise and of new treatment and procedures which may have become available since the Advance Decision was signed.”²⁶ I suggest that this concern is equally valid today.

3.13 Allowing people to set out in advance the types of treatment they would, or would not, be prepared to accept assumes a degree of medical knowledge which few lay people possess. Even if one researched the subject and found out all the possible conditions one might experience, and all the possible treatments which might be available (which is in itself hardly a realistic prospect), the fact is that medicine is always advancing. What is extraordinary today may well be commonplace tomorrow, and new treatments become possible almost every day. All these factors would call into question the validity of an Advance Decision.

3.14 The British Medical Association has said that:

While the BMA recognises the advantages in terms of encouraging openness, dialogue and forward planning, it is not proselytising on this issue (Advance Decisions). The BMA Code of Practice draws attention to disadvantages as well as benefits of anticipatory decision-making. Health professionals and the public should be aware that treatment decisions are complex, medicine is uncertain, practice is constantly evolving and there is always the possibility of a mistaken diagnosis. Views also change about what constitutes a tolerable existence. Advance Directives cannot encompass unforeseen possibilities and options. Therefore . . . the BMA is not actively encouraging people to undertake the risks associated with committing themselves in advance.²⁷

3.15 Unlike Lasting Powers of Attorney, Advance Decisions would not have to be registered under the terms of the draft MIB, allowing for them to be made orally. Thus all that would be needed for such a statement to be binding would be someone to say: “I heard Mrs Smith say she didn’t want to be treated if she was in this condition.” In such circumstances it would then be illegal for the doctor to give the patient treatment—presumably including tube delivered food and fluids. This would make lethal neglect compulsory, which is clearly unethical.

3.16 The draft MIB creates punishments for “concealing or destroying” Advance Decisions, including those which refuse “medical treatment” (a term which is taken to include assisted food and fluids.) Thus doctors could be punished for saving a life, a travesty of their traditional role, and of the instruction in the Hippocratic Oath “*primum non nocere*.”

4. LASTING POWERS OF ATTORNEY

4.1 I note that the draft MIB allows people to appoint a Lasting Power of Attorney, who would be able to act on welfare matters (including “healthcare”) as well as financial matters.

4.2 While LPA’s may have a legitimate role to play in ensuring that incapacitated people receive beneficial healthcare, they can also have huge dangers when they are involved in making decisions about issues concerning life and death. These dangers are highlighted by the case in Florida USA of Mrs Marjorie Nighbert, an 83 year old lady who was in a nursing home after a stroke. She was deprived of a feeding tube by a Court order on 23 March 1995. A nurse heard her ask “Will you give me a little something to eat?”

4.3 Mrs Nighbert was not given food by mouth on the pretext that there was a danger of her choking. A nurse who gave her some milk was reprimanded. She had never signed an Advance Directive, but had given Power of Attorney to her brother, who forbade tube feeding. A judge decided she was “not mentally competent” to revoke the Power of Attorney giving her brother power to have her starved to death, and she died on 6 April 1995.

4.4 It might be objected that this situation would not arise under the draft MIB because it allows for revocation by “inconsistent act.” But what if the family are the ones who witness such an act and they, for reason of personal gain or any other reason, choose not to convey information about it to those who are not feeding the incapacitated person? (see section 3.11) The MIB needs to include a clause making it clear that if any person named as an LPA sets in motion an action on behalf of the incapacitated person with the purpose, or a purpose, of causing or hastening his or her death, the LPA would be guilty of a criminal offence.

5. THE COURT OF PROTECTION

5.1 The Court of Protection is a contradiction in terms because one of its chief functions would be to underwrite decisions to withdraw or withhold food and fluids from vulnerable people, and thus to cause their deaths. It would be impossible for anyone opposed to such medical killing to sit on the Court of Protection since s/he could take no part in its function of supporting decisions that mentally incapacitated people be starved and dehydrated to death.

²⁶ Report of the Select Committee on Medical Ethics. Printed 31 January 1994. Paragraphs 263 and 264.

²⁷ “Refusal of Treatment” *End of Life Decisions: Views of the BMA*. June 2000.

5.2 Rosie Winterton, Health Minister, has said:

The Department of Health welcomes the publication of the draft Mental Incapacity Bill . . . These are proposals to provide increased protection and autonomy for many of our vulnerable client groups, including those with a learning disability, older people with dementia and those with mental health difficulties.²⁸

If starving and dehydrating vulnerable people to death is “protection” then what hope is there of any patient being treated according to traditional, clinical “best interests” criteria?

5.3 It should be noted here that the British Medical Association have argued that cases of withholding or withdrawing food and fluids from people who have advanced dementia, or who have had a severe stroke should not “routinely be subject to Court review.”²⁹ The Court of Protection could actually provide the means by which vulnerable people would be pushed into death, making a mockery of its name.

6. THE GOVERNMENT’S STATED “OPPOSITION TO EUTHANASIA”

6.1 The Government has repeatedly claimed that it is not in favour of legalising euthanasia.^{30 31} However, in supporting the provisions of the MIB, the Government is also supporting the killing by neglect of the most vulnerable of people. The Government has claimed that this killing by neglect is not euthanasia, because it defines “euthanasia” very narrowly as:

A deliberate intervention undertaken with the express intention of ending a life.³²

6.2 The claim that killing by starvation and dehydration is not “euthanasia” because it involves withholding or withdrawing “treatment” rather than initiating it, is untenable. Killing by starvation and dehydration is just as much euthanasia as giving a lethal injection, and the intent to cause the patient’s death because his or her life is regarded as having no value is identical.

6.3 If the Government is truly serious in its stated opposition to euthanasia, and really wants to advance the true best interests of people who are mentally incapacitated, it should make it clear that whatever a person may have requested in an Advance Directive, there is no such thing as a “life not worth living” and that Advance Directives with a suicidal intent ought not to be acted upon. Incapacitated people, like all human beings, are entitled to the best available treatment, given in their clinical best interests.

6.4 The draft MIB provides for punishment of a person “ill treats or wilfully neglects” a mentally incapacitated person in his or her care, but allows withholding or withdrawing food and fluids with the purpose of ending life. Starving and dehydrating a vulnerable person to death is in itself “wilful neglect.”

7. DEFINITIONS USED IN THE MIB

7.1 It has been noted that following the Bland and Law Hospital decisions assisted food and fluids are regarded as “medical treatment” which can legitimately be refused in advance. I suggest that this is not a helpful way to approach and manage disabling conditions.

7.2 Food and water are basic human necessities, and the European Convention on Human Rights has ruled that there is no “right to die” implicit in Article 2 of the Human Rights Act 1998 which states that “everyone’s right to life shall be protected by law. No one shall be deprived of his life intentionally.”³³ I suggest that the draft MIB is incompatible with provisions in the ECHR and the Human Rights Act to provide “practical and effective protection of the right to life.”³⁴

7.3 I anticipate that the objection that will be raised to point 7.2 is the case of Mrs M and Mrs H in which Dame Elizabeth Butler-Sloss ruled that the two women were enduring a “living death” and should be “allowed to die with dignity.”³⁵

²⁸ BBC Press Release on publication of the Government’s Mental Incapacity Bill 27 June 2003.

²⁹ Withholding or Withdrawing Life-prolonging Medical Treatment: Guidelines for decision making. Published by the BMA 1999.

³⁰ Making Decisions the Government’s proposals for making decisions on behalf of mentally incapacitated adults, published in October 1999, contains the statement “The Government wishes to make absolutely clear its complete opposition to euthanasia which is, and will remain, illegal”.

³¹ The Parliamentary Secretary to the Lord Chancellor’s Department, Baroness Scotland of Asthal said “We are determined that our proposals should not lead the way—through the back or any other door—to euthanasia. The noble Baroness (Baroness Finlay of Llandaff) may be confident that this is not our intent.” House of Lords debate on Mental Incapacity 18 December 2002. Hansard Col. 774.

³² Letter from Simon Vinogradoff, Medico-Legal Branch, Family Policy Division, Lord Chancellor’s Department to Alison Davis 29 November 1999.

³³ European Court of Human Rights ruling on the case of Diane Pretty 29 April 2002.

³⁴ Human Rights Act 1998.

³⁵ “Court says ‘living death’ two may die” by Andrew Norfolk. *The Times* 7 October 2000 “Rights Act does not bar mercy killing” by Frances Gibb. *The Times* 26 October 2000.

7.4 Dame Elizabeth said that this was not contrary to Article 2 of the Human Rights Act (the right to life) or Article 3 (Freedom from degrading or inhuman treatment or torture) because the decision to deny them food and water was consistent with the Bolam test³⁶—ie that it was a decision taken by a doctor in accordance with the “accepted professional view and practice of a body of doctors skilled in that area of medical practice.” However, Bolam is only a test of clinical negligence, not a test of criminal homicide, a point which Dame Elizabeth appeared to overlook in her judgement. Profoundly disabled people have the same right to life as everyone else, and do not achieve “dignity” only in death, as Dame Elizabeth implied.

7.6 The Making Decisions leaflets issued by the Lord Chancellor’s Department in April 2002 refer to assisted food and fluids as “artificial means” of keeping a person alive. The term refers to Court decisions that “artificial nutrition and hydration” are “medical treatment.” The MIB allows Advance Directives which refuse in advance “life prolonging treatment” (10.4.b).

7.7 Even the British Medical Association, which supports killing vulnerable people by starvation and dehydration, has admitted that

It is recognised that neither the nutrition nor the hydration is, in fact, artificial, although the method of delivering it is.³⁷

7.8 Food and fluids have the same purpose for profoundly disabled people as for all other human beings (indeed for all living things). The need to be assisted with nutrition does not render food and fluids “artificial.”

7.9 There is nothing “artificial” about tube or PEG feeding. As the social commentator Melanie Phillips has noted with reference to Tony Bland:

The proper analogy . . . would be some kind of mechanical device to digest food if the stomach had packed up. Mr Bland’s digestive system still works; he simply cannot feed himself. As a result he depends on others to get the food inside him . . . if someone had suffered, say, a catastrophic stroke and was entirely dependent on others to feed him with a spoon, we would say that was merely assisting him to be fed . . . it is surely perverse to conclude that this particular manner of assisting him to be fed transforms nutrition into medical treatment.³⁸

8. A PERSONAL FEAR

8.1 The problems I raise in these comments have a particular personal resonance for me. As stated earlier I have spina bifida, emphysema and osteoporosis, and use a wheelchair full-time. Eighteen years ago I decided I wanted to die, due to a combination of severe physical pain and other factors. It was a settled wish that lasted about ten years, and during the first five of those years I made serious suicide attempts several times. I was saved only because my friends refused to accept my view that my life had no value, and made sure I was given emergency treatment in hospital, which was given against my will. Then I was extremely angry with them; now I am eternally grateful. It should be noted that my physical pain is now as least as bad as it was then. Then, as now, when my pain is at its worst I cannot move, speak or think and this can go on for hours, with no prospect of relief. Indeed it is almost certain that the pain will get worse. What has changed is not my medical condition, but my outlook on life.

8.2 If Advance Decisions had been legally binding then, I have no doubt that I would have written one. I would not have received the emergency treatment that saved my life, in accordance with my wishes expressed in advance, and would thus have been denied the chance to re-establish a sense of the value of my life. I sincerely “wished” to die and “felt” my life had no value, but, as often happens, those “wishes and feelings” did not correspond with what was truly in my best interests. The draft MIB fails to point this out—indeed it strongly implies that any sensible person would possess an Advance Decision to be acted upon in case of mental incapacity.

8.3 The draft MIB would add more categories of people to those doctors already push into death because of a judgment that they have no value and are “better off dead.” I am painfully aware that members of the medical profession already abort babies with my condition, up to the moment of birth, and that members of this Government, including the Prime Minister Tony Blair, voted for that to be allowed. I also know that newborn babies are not infrequently sedated and starved to death by doctors, solely because they would otherwise grow up to be like me.

³⁶ Bolam v Friern Hospital Management Committee [1957] 1WLR 582.

³⁷ Guidelines on Withholding or Withdrawing Life-Prolonging Medical Treatment. Paragraph 3.4 p. 7. *British Medical Association* 1991.

³⁸ “When grief should not be the key” by Melanie Phillips. *The Guardian*. 27 November 1992.

8.4 I am genuinely frightened about what would happen to me if I were to become mentally incapacitated and unable to speak for myself. Doctors are already demonstrating every day that they are prepared to kill those like me, for no other reason than that they are like me. If the draft MIB becomes law, doctors would seem to have every justification for killing me were I to be unable to speak for myself.

9. A REQUEST TO THE GOVERNMENT

9.1 I appeal to the Government to act to protect the true, clinical, best interests of the most vulnerable people in our society, and to make provisions for the most profoundly disabled people to be protected from the harm of being starved and dehydrated to death. Unless it does so, this Government will be guilty of killing in the name of "123" protection—a contradiction in terms and the most serious derogation of its duty of care for those who cannot speak for themselves.

August 2003

97. Memorandum from Catherine Crabtree (MIB 339)

I write as a solicitor in the City of London deeply concerned by the proposals set forth in the draft Mental Incapacity Bill ("MIB"). In response to the Committee's request for submissions from members of the public I set out below the key points of my concerns.

1. THE PROPOSALS OF THE MIB

1.1 I understand that the MIB proposes to:

- (a) give binding status to a so-called "advance decision" to have one's medical treatment withheld in circumstances of mental incapacity, regardless of the method in which such decision was communicated, the age of the decision, or how hypothetical the condition; and
- (b) establish "Lasting Powers of Attorney" which allow a person to appoint another to act on their behalf on matters which include healthcare in the event that they lose mental capacity in the future.

1.2 Under either (a) or (b) medical treatment could be refused to a mentally incapacitated person. Following the case of *Airedale NHS Trust v Bland*³⁹ "medical treatment" is considered to include food and fluids delivered by tube.

2. A DENIAL OF THE ABSOLUTE VALUE OF LIFE

2.1 Generally speaking, the law would consider the withdrawal of food and fluid to be a method of killing. A person who denied food and drink to a child in his care to the point of death, for example, would be considered to have murdered that child.

2.2 It is a legal principle that one cannot consent to one's own killing. However, this permitting of a withdrawal of food and fluids allows that, given some degrees of handicap, one can consent to one's own killing. The necessary implication of this is that there are some classes of people who the law considers deserve fewer protections than others. The law will provide cast-iron defences for the strong and healthy, but will dilute these protections for those suffering from mental handicap.

2.3 This reveals the fundamental thinking behind the MIB (and behind the apparent current thinking of the Family Division of the High Court)—that some lives are more worthy of protection than others. This is a worrying principle to introduce into the legal system. Assessing lives according to their "value" could lead to obvious and horrific consequences. Why do we recoil at the idea of peacefully killing in its sleep a child born into a poverty stricken and war torn country who is bound to face terrible suffering? Why are we horrified by the case of Harold Shipman who killed elderly patients without (it seems) causing them any fear or distress? It is because we recognise that life itself has a value which is not contingent upon the circumstances in which it is lived. This is an instinctive and fundamental ethical principle which has historically been upheld by our legal system. It would be attacked to the core if the MIB were to become law.

³⁹ [1993] AC 789.

3. PUNISHMENT OF OBJECTORS

The MIB creates punishments for “concealing or destroying” an advance refusal of medical treatment. This is tantamount to a denial of freedom of conscience. Most major world religions consider the value of life to be absolute rather than relative and members of these religions would clearly object to playing a part in the premature death of any human being. Such a provision would prevent these people and other objectors on ethical grounds from legally following their peacefully held beliefs.

4. PRACTICAL CONCERNS

In addition to my fundamental concerns about the eroding of the value of life, there are several practical concerns which should, I suggest, in themselves be sufficient to prevent the MIB from becoming law:

- (a) It is impossible to draft around the possibility that a patient may change his/her mind about an advance decision. There will always be the risk that a doctor will be acting against a patient's wishes when (s)he acts to bring about the ending of their life.
- (b) An advance decision may be made in any form and need not be registered. It can therefore be made orally to any person. The potential for abuse here by a malicious relative or acquaintance is evident.

In the strongest possible terms, I therefore urge the Committee to recommend that the MIB does not become law.

August 2003

98. Memorandum from Advocacy Partners (MIB 821)

1. Advocacy Partners provides independent advocacy to people with disabilities, mainly in South West London and in Surrey. Established in 1981 the organisation largely works with people with profound learning disabilities and also works increasingly with older people with disabilities, including those affected by dementia. Advocacy Partners is a registered charity and a company limited by guarantee.

2. We broadly welcome the proposals in the draft Mental Incapacity Bill (“the draft Bill”) and believe that it helps to fill a significant gap in legislation that at present negatively affects many of our clients as well as carers and professionals who support them. However we believe that substantial amendment is needed if the draft Bill is to enhance rather than to reduce the autonomy of people whose capacity to make particular decisions may at times be questioned.

3. We have, where possible, answered the specific questions posed for the Scrutiny Committee and provided more detailed comments on a number of areas of the draft Bill.

4. Was the consultation process preceding the publication of the draft Bill adequate and effective?

The issues addressed by the draft Bill have been published and consulted on since the late 1980's, we believe that the process has been adequate and effective.

5. Are the objectives of the draft Bill clear and appropriate?

It is clear that the objective of the draft Bill is to provide a legislative framework where none previously existed for people who lack capacity. It would be more appropriate, and render a greater service to many people whose capacity may at times be questioned, if legislation set as a second objective providing a framework and support to enhance capacity.

6. Are the proposals in the draft Bill workable and sufficient?

Greater safeguards are needed specifically in relation to the general authority, clarity is needed about how capacity will be assessed and by whom. An entitlement to independent advocacy is required to enhance the capacity of people to make decisions and to protect the autonomy and rights of people who may nevertheless lack capacity to do so. For these reasons we do not consider that the proposals are workable or sufficient.

7. Are there relevant issues not covered by the draft Bill which it should have addressed?

Yes, entitlement to advocacy and to support to assist communication and enhance capacity.

8. In what other ways might the draft Bill be improved?

Please see detailed comments below.

9. Approach to incapacity

9.1 We welcome the definition of incapacity relating to the ability to make a particular decision.

9.2 We believe that an adequately resourced information, awareness raising and training strategy, as well as the code of conduct and guidance, will be required to reinforce this understanding of incapacity. As practitioners well used to the vagaries of interpretation of legislation and policy, we are concerned that

without this the enactment of legislation will lead perversely to significant number of people being considered by professionals and others to be “incapable” without sufficient regard to a specific decision or time.

10. Inability to make decisions

10.1 We welcome the requirement that all practicable steps must be taken to help a person to make a decision and that these must have failed before the person is treated as unable to make that decision.

10.2 We believe that this requirement needs to be accompanied by explicit reference within the proposed legislation to:

- A requirement that reasonable steps are taken to provide information at a time and in a way that is most helpful to the individual in supporting their ability to make a decision.
- A requirement in relation to major decisions¹ that appropriate professional advice on methods of communication to enhance capacity is wherever practicable sought and acted upon.
- A duty on relevant statutory authorities to provide such advice and support in line with this advice where required.
- A right to provision of independent advocacy to enhance the person’s capacity, at least where triggered by specific major decisions and events (some of which are described in this paper).

11. Best interest framework

11.1 We welcome the best interest framework. We have used the (similar) framework outlined in the consultation paper *Who Decides* over a number of years, including in our policies on confidentiality and referrals, in appraising options on behalf of clients and in providing supervision to advocates working with people who lack capacity in relation to particular decisions. We have found these to be appropriate and workable.

11.2 We are concerned that the test for compliance 4(4) needs to be set higher in many cases. It ought to be explicit that donees of a L.P.A., deputies and employees of health and social care agencies making major decisions under the general authority must have due regard to the factors outlined in 4 (2) wherever it would be reasonable for them to do so and 2(3) in any case.

12. The general authority

SCOPE OF THE GENERAL AUTHORITY

12.1 Explanatory notes suggest the application of this clause to “day-to-day decisions”. We note that this is not made explicit in the draft Bill.

DAY-TO-DAY DECISIONS

12.2 We broadly agree that such an authority is helpful in providing protection to carers and professionals in supporting people who are unable to make some day-to-day decisions.

12.3 The draft Bill does not provide a formal process of assessing capacity prior to the general authority being used. We appreciate that there may be a tension between ensuring that people are supported to make their own decisions whenever practicable and the need to reduce potential intrusion and unhelpful formality, particularly where this may jeopardise care provided by relatives and other unpaid carers. Nevertheless we are concerned that in the absence of assessment of capacity, legislation based upon the draft Bill runs the risk of legitimising paid staff and carers making decisions on the part of a person who can be supported to do so himself.

12.4 We believe that further consideration is needed about how to achieve the right balance here and that community care assessment and care planning may provide tools to achieve this in some cases.

12.5 There is also an opportunity to ensure that proposed legislation encourages the provision of guidance, resources and training on supporting people’s autonomy in these day-to-day decisions. Such materials need to be relevant to service users, professionals, carers and those who support them.

MAJOR DECISIONS MADE UNDER THE GENERAL AUTHORITY

12.6 In the draft Bill the general authority appears to apply in deciding major questions on behalf of a person believed to lack capacity, such as where to live, significant medical treatment, contact and use of restraint.

12.7 We work with a large number of men and women who face very major decisions, for example about where they will live in the future. Many of these people lack capacity to make these decisions. In our view, the draft Bill does not provide sufficient safeguards for the use of the general authority in this situation.

⁴⁰ “Major decisions” will be used in this paper to include decisions about where to live, significant medical treatment, contact and use of restraint.

12.8 We suspect that there are likely to be a number of different proposals as to how safeguards can be strengthened here. We suggest that in relation to major decisions:

- (i) It should be specified that the general authority should be exercised in relation to significant medical treatment by the relevant health professional, and
- (ii) In the case of people provided with health and social care services, a formal assessment of capacity must take place, and a recorded best interest decision must be made prior to major decisions being enacted using the general authority, except in the case of emergency treatment/action.
- (iii) A duty is placed on PCTs and local authorities that if they are aware of a person who faces a major decision that s/he lacks capacity to decide, they will ensure that independent advocacy is made available to the person.

THE GENERAL AUTHORITY AND USE OF RESTRICTIVE PHYSICAL INTERVENTIONS

12.9 In relation to s. 7, we are concerned that even with the above amendments, there may not be sufficient safeguards to the use of restrictive physical interventions for non-emergency situations. We believe that the proposed legislation presents an opportunity to provide greater clarity and greater protection here. This should include a right to advocacy. Consideration should also be given to introducing a requirement that a Court order is sought in some circumstances, and a formal procedure followed in all cases of non-emergency restrictive physical interventions known to statutory authorities.

13. Lasting Powers of Attorney (LPA)

13.1 From our work, especially with older people with disabilities, we believe that the creation of LPAs has the potential to be of considerable benefit to people who may experience declining capacity or wish to have safeguards in place in case this occurs.

13.2 We have experience of abuse of the EPA system and are concerned that the position of donors of LPA is strengthened by clear information to potential donors and the availability of guidance, advice and where necessary advocacy.

13.3 In our experience statutory authorities and service providers are sometimes hesitant to intervene where they suspect that EPAs (and appointeeship) may be being misused. As a consequence we believe that it is important that, prior to enactment of legislation, effective information is provided to statutory authorities, service providers, advice and advocacy agencies on the use of LPAs and about mechanisms to challenge suspected inappropriate use of these.

14. Deputies

14.1 It appears from 19(1) that the draft Bill appears to wish to keep to the minimum any restrictions on who may become a deputy. We believe that some factors to be taken account of in the selection of a deputy ought to be provided and that issues of potential conflict of interest for deputies must be addressed.

14.2 In order to provide sufficient safeguards, we believe that the Court should have the power to require a local authority or PCT to arrange for the appointment of an independent advocate where the nature of the decision is such that further checks and balances are needed. This may be especially relevant if there are potential conflicts of interest for the deputy and where the powers of the deputy are likely to span a number of issues or may be required for a protracted period of time.

14.3 We agree that in general the powers of the deputy should be as limited in scope and duration as possible. We think that to provide the most assistance to, for example, people with profound learning disabilities, the appointment of a deputy over a considerable period of time may nevertheless, in some circumstances, ensure fuller account is taken of the person's preferences and interests than would be the case with several appointments or repeated reference to the Court.

15. Assessing capacity

15.1 We appreciate the draft Bill provides for a Court to determine whether an individual has capacity to make a decision. We believe that the draft Bill also needs to address how capacity will be assessed, by whom and whether this can be challenged other than by application to the Court.

15.2 Consideration needs to be given as to any conflict of interest that may arise for professionals and organisations making such assessments. A right to independent advocacy to provide support and safeguards in the assessment process must be included for the person being assessed.

August 2003

99. Memorandum from the Afiya Trust (MIB 822)

BACKGROUND TO ORGANISATION CO-ORDINATING THE RESPONSE

THE AFIYA TRUST

1. The Afiya Trust is a national charity based in London. Formed in 1995 by the King's Fund as the Black Health Foundation, today the Afiya Trust is a home to projects that involve carers' support, provision of multi-lingual information for families of people living with cancer, community involvement, capacity building and mental health.

2. The Afiya Trust generates, supports and maintains national and local networks concerned with the promotion of Black and minority ethnic (BME) peoples health and community care equality issues.

3. The Afiya Trust co-ordinated this collaborative response to the proposed Mental Incapacity Bill. The organisations involved are listed in Appendix 1.

SUMMARY

4. BME Communities are particularly vulnerable when it comes to the causes of mental incapacity. They are affected, for instance, by a higher rate of strokes and mental ill health. BME people with learning disabilities have been shown to face greater disadvantage and the BME population, like the rest of the population, is an ageing one.

5. In the process of consultation the views ranged from total opposition to the bill to broadly welcoming it, but with strong reservations. No respondent was in favour of the bill without modifications. The strongest opposition came from disability organisations, especially those that are run by people with learning disabilities. They feel the Bill gives too many rights to carers and takes away rights from disabled people.

6. There are a number of concerns about the interpretation and implementation of the Bill that arises from the experience of BME communities which is demonstrated by related research of how legislation works in practice. It is felt that some of these issues are best addressed within the Bill and not just left to codes of practice.

CONSULTATION QUESTIONS

Was the consultation process preceding the publication of the draft Bill adequate and effective?

7. Organisations did not know about the Bill or any preceding consultation. There are no specific BME groups on the Decision Making Alliance. This Bill was not as well publicised in the media as the Mental Health Bill and therefore many interested organisations are unaware of it. Where organisations are now aware of it the time factor and resource limitations makes it difficult for them to consult with their constituents.

Are the objectives of the Bill clear and appropriate?

8. Supporting documentation, such as the summary and frequently asked questions on the Constitutional Affairs website, makes the objectives of the Bill clearer. However, the Bill itself is not as clear as it could be in what it intends.

Does the draft Bill meet these objectives adequately?

9. It is not felt that the Bill addresses these objectives adequately. Suggestions have been made to improve this. There are concerns from Black carer organisations that the Bill actually puts more pressure on carers as there are implications of added legal responsibilities placed on them. Advocacy and support for carers are both needed. The added cultural and language difficulties faced by BME carers when accessing information and support is a particular concern. This has been well documented.

Are proposals in the draft Bill workable and sufficient?

10. There are a number of areas that BME consultees would like to address.

PART 1.

PERSONS WHO LACK CAPACITY

11. This definition is acceptable.

INABILITY TO MAKE DECISIONS

12. Under 2 (1) (a)–(c) do all these conditions need to apply?
13. In 2 (1) (d) insert “in a language of his choice after ‘whether by talking’”.
14. Under 2 (2) add “or makes a decision that is not in keeping with norms of broader society”.
15. Who decides if the decision is just an unwise decision or there is incapacity? Functionality tests need to be appropriate and take into account cultural, religious and language issues and perspectives. This would ensure that people working within the Incapacity Act fulfilled their obligations under the race Relations Amendment Act.

PRESUMPTION AGAINST LACK OF CAPACITY

16. This section is welcomed.

BEST INTEREST

17. This section lacks any reference to a persons cultural or religious beliefs which we believe would be material in determining their best interests. We feel this should be a requirement of the Bill. Implementation of this section also needs to take into account communication difficulties and the need for support should include bilingual advocates.
18. Under 4 (2) (b) “the need to permit and encourage him to participate” is welcomed. However, how will this be enabled? Again we feel access to an independent advocate should be part of the Bill.
19. We presume that 4 (2) (d) (ii) “or interested in his welfare” includes appropriate agencies or advocates.

THE GENERAL AUTHORITY

20. This section seems to give carers very wide powers. We are concerned about the statements “any” person and “any” form of care. Should this not be more clearly defined? We feel there should be a distinction made between families and friends and formal carers. For instance a parent of an adult with severe learning difficulties might be better placed to communicate with that person than new formal carers. This can happen when an adolescent moves from children to adult services. There should be something about who has general authority and to what extent. There should be a different section for formal/paid carers who might also be covered by employment law and other legislation such as the Care Standards Act.
21. There is concern that the Bill does not give enough support to caring carers. Carer organisations felt that carers would be making key decisions with legal implications and have no real protection. However, there is a danger that “abusing carers” might be able to get around the “best interests” section due to their knowledge of the person with mental incapacity. The general authority needs more checks and balances.

LASTING POWERS OF ATTORNEY

22. This is a positive clause. However what happens with fluctuating capacity? Clarity is needed about when this is applied.
23. How will people exercise this power, which can be wide ranging, and how will it be monitored to ensure powers are not being abused?

APPOINTMENT OF DONEES

24. When more than one donee is appointed clarity is needed on what happens if there is a dispute between donees—do they have to go to the Court of Protection?

REVOCATION OF LASTING POWERS OF ATTORNEY

25. The person with mental incapacity needs access to independent advocacy and support. Access to independent advocacy is needed for the whole process but in particular in this section because of any difficulties which might occur with family relationships. It might be difficult for someone to revoke a lasting power especially if a donee is a family member.

POWERS TO MAKE DECISIONS AND APPOINT DEPUTIES—ALL RELEVANT SECTIONS

26. Deputies need to be aware of relevant cultural and religious beliefs of the person with mental incapacity. This would fulfil obligations under the Race Relations Amendment Act. They may be required to be able to speak the relevant community language.

ADVANCE DECISIONS TO REFUSE TREATMENT

27. There are a number of points to be made under this provision:

- For BME communities independent advocates can enable people to record their wishes.
- The Bill makes no mention of people with different language needs.
- This provision should extend to people covered under the new Mental Health Act as long as they were not a risk to others.
- it is also strongly recommended that a section on advance directives is included where people can set out what they would like to happen as opposed to just a refusal of treatment.

EXCLUDED DECISIONS

28. We presume that the excluded decisions include decisions on termination of pregnancy.

CODES OF PRACTICE

29. The codes of practice all need to address language issues and how people can be supported to make advance decisions.

ILL TREATMENT AND NEGLECT

30. The definition of ill treatment should take into account cultural and religious issues.

PART 2.

COURT OF PROTECTION

31. Staffing should reflect BME communities. Staff need to understand and be trained to deal appropriately with the issues that affect Black and minority ethnic people with mental incapacity issues. This includes the Public Guardian and the Lord Chancellors visitors. They need to adhere to the Race Relations Amendment Act.

32. What will be the limits on court appointed deputies?

33. Power to call for reports 39 (5) ensure that cultural diversity is used in the interpretation of mental and ethical matters.

SCHEDULE 3

34. Part 3 (7) Add donor's partner to list.

Might lessons be learned from similar registration already implemented in Scotland or elsewhere?

35. There are some key differences between this Bill and the Adults with Incapacity Act in Scotland.

- Scotland has a list of principles but the Bill has a checklist, which is thought not to be as strong as principles.

- Scotland also has a number of checks and balances, including three monthly monitoring by local authorities and annual monitoring by the Mental Welfare Commission. In the proposed Bill the power to call for reports from local authorities and the Lord Chancellor's visitors does not cover regular monitoring.
- in Scotland the Court appoints guardians but does not make decisions itself on behalf of a person with incapacity.
- In Scotland medical practitioners carry out functional tests, and the codes of practice stress multidisciplinary assessment. We are not advocating that medical practitioners be specified as carrying out functionality tests, as evidence from mental health has demonstrated that they do not have the cultural understanding needed to appropriately interpret responses. However, Scotland are clearer on who will carry out functional tests.

36. Early feedback on the implementation of the Act has confirmed that BME communities are on the whole unaware of the Act and its implications.

37. The general consensus from mainstream health and disability organisations is that it has empowered carers, although there have been some legal challenges where solicitors are seeking extra powers under the Act for carers which are inappropriate to the level of decision making a person with incapacity can still make. This has been dealt with by the Sheriff's court.

Are there relevant issues not covered by the draft Bill that it should have addressed?

38. In summary there are four main areas that need to be addressed in the Bill. These are:

- Cultural and religious sensitivity.
- The need for advocacy and support, as there is a need to ensure that someone is involved in decision making even if they lack the capacity to make decisions.
- Protection for those with mental health issues.
- Facilities for language support.

In what other ways might the draft Bill be improved?

39. Other concerns include how will functional tests be carried out and will enough attention be paid to cultural, language and religious issues? Proper assessments are very important and experience has shown that BME people have been misdiagnosed. Will all practical steps be taken to enable someone to communicate? Although there is a recognition that people communicate differently this seems to be a very broad definition and the simple fact that someone might speak another language does not seem to be acknowledged. The need for advocacy support of some kind, not only for the person with incapacity but also their carers is important.

40. There is a concern that paid/professional carers will make decisions on where someone lives, their finances and welfare. Given the results of research and public enquiries on the existence of institutional Racism we find this quite disturbing. How will the Race Relations (Amendment) Act be taken into account?

41. BME communities are unlikely to be aware of the Bill and the consequent Act. Therefore it is important to target information towards these communities.

42. It would be useful to consult with BME organisations in the drafting of the Codes of Practice.

August 2003

Annex

DRAFT MENTAL INCAPACITY BILL CONSULTATION PARTICIPANTS

Those that attended the consultation meeting or responded by e-mail:

<i>Name</i>	<i>Organisation</i>
Dianne King	Lambeth Social Services
Millie Reid	GLAD
Mike Took	Making Decisions Alliance
Daniel Mwamba	Afiya Trust
Claire Felix	Rethink
Neema Mandalia	Afiya Trust
Shahid Sardar	Diverse Mind
Peter Blackman	Afiya Trust
Suman Fernando	Psychiatrist
Meena Patel	Afiya Trust
Raymond Leung	Minority Ethnic Learning Disability Initiative Limited

<i>Name</i>	<i>Organisation</i>
Mercy Jeyasingham	Kings Fund
Bakhtiar Homoz	Songhai
Richard Klamer	Turning Point
Hellen Murshali	Refugees
Linda Kerr	Enable Scotland
Jan Killeen	Alzheimer's Scotland
Heather Anderson	Scottish Human Services Trust

Those invited to attend the meeting or to respond by e-mail but did not respond.

<i>Name</i>	<i>Organisation</i>
Frank Keating	Sainsbury Centre Mental Health Foundation
Helen Tomkys	DOH
Kevin Mantle	DOH
Melba Wilson	Chair, Wandsworth Primary Care
Safron Simmonds	Tasha Foundation
James Nazroo	Afiya Trust trustee
Jazz Bhogal	Afiya Trust trustee
Lord Michael Chan	Chairman of Afiya Trust board of trustees
Lydia Yee	Afiya Trust trustee
Tahera Aanchawan	Afiya Trust trustee
Yasmin Gunaratnam	Afiya Trust trustee
Denise Forde	Afiya Trust
Zelalem Kebede	Afiya Trust
Chinyere Inyama	Inyama Associates (solicitors)

100. Memorandum from the NHS Confederation (MIB 823)

The NHS Confederation is the independent membership body for the full range of organisations that make up the NHS across the UK. We work to improve health and social care by influencing policy and the wider public debate, promoting management excellence and supporting members through networking and information exchange.

The Confederation welcomes the opportunity to comment on the Bill before it begins its parliamentary journey. The Confederation broadly supports the principles behind the reforms which re-orientate the decision making process for people lacking capacity towards the individuals concerned and give precedence to their needs and wishes.

1. WAS THE CONSULTATION PROCESS PRECEDING THE PUBLICATION OF THE DRAFT BILL ADEQUATE AND EFFECTIVE?

We feel that the dissemination of information about the bill was sufficiently wide and included the broad range of stakeholder organisations and individuals affected. The organisation of several regional diagnostic events also provided a useful interactive forum for exploring the impact of the legislation and for feeding back initial comments about the bill. The Confederation strongly supports the focus on people with learning disabilities through the publication of tailored materials and organisation of workshops. It might also be useful to gauge the specific responses of other affected groups—eg older people’s groups, NHS and social care professionals, carers in the forthcoming months of consultation.

2. ARE THE OBJECTIVES OF THE DRAFT BILL CLEAR AND APPROPRIATE?

The NHS Confederation wholeheartedly supports the objectives of the Bill—to empower people who lack capacity, whilst also providing protection and clarifying the statutory framework for them, their carers and for other professionals and organisations also affected.

The Confederation believes the presumption of capacity inherent in the Bill is an important and positive principle in the legislative reform of mental incapacity. The move within the Bill to encourage planning for incapacity through Lasting Power of Attorneys and advance decision-making is also a sensible approach, which will avoid ambiguity and disputes for individuals and healthcare professionals and providers.

3. DOES THE DRAFT BILL MEET THOSE OBJECTIVES ADEQUATELY?

The Bill provides a clear framework for the establishment of mental capacity/incapacity and the preceding and subsequent decision making processes for the person concerned. The inclusion of decisions relating to healthcare and treatment is a welcome addition to the Bill and creates a clear framework for service users and providers.

The “best interests” test in S4 gives autonomy to the individual and encapsulates the right degree of flexibility and inclusivity. The emphasis on the individual’s past and present wishes and the “least restrictive” course of action should ensure that the outcome reflects the person’s wishes and takes into account all the relevant information.

4. ARE THE PROPOSALS IN THE DRAFT BILL WORKABLE AND SUFFICIENT?

Determining capacity

Organisations and agencies will be required to interpret and implement the legislative principles in a wide range of situations and services concerning individuals with vastly different needs and wishes—eg people with learning disabilities, older people with degenerating mental health problems and people who have undergone a stroke. It is therefore crucial that the Code(s) of Practice, accompanying the legislation provide the right level of support and guidance—to enable the professionals and organisations concerned to give effect to the true spirit of the Bill. This is particularly relevant for the mechanics of the “individual act” assessment of mental capacity. The NHS Confederation supports this discriminate approach, particularly where people’s capacity may fluctuate, but is keen to ensure that the practical application avoids creating a bureaucratic, time-consuming and intrusive process for users, clinicians and service providers.

General Authority

The General Authority in the Bill creates a clear basis for intervention when a person is lacking capacity. In the realm of healthcare it is foreseeable that the views of patients, carers and clinicians will sometimes differ. The Bill is therefore potentially an important tool for authorising treatment and for providing clinicians with the confidence to intervene. The Code(s) of practice need to address the different scenarios which might arise and clarify the clinical processes.

Lasting Power of Attorney

The Confederation supports the construction of the LPA facility reinforced by the best interest test of S4, as a flexible mechanism for effecting the individual’s wishes. The measures to protect the donee (s13) and the requirement for registration with the Public Guardian (Schedule 1 Part 2) backed up by the Court’s intervening power (s22) will act as important checks on the function. There is however a need for clarity about how the system will operate—particularly where the individual has appointed several donees, or where the Court has appointed deputies in some decision making areas. The donee may be required to make quick decisions about vital treatment—it is crucial that the framework enables him to interact effectively with the other bodies.

Court of Protection

The extensive powers of the Court in various areas including healthcare decisions are balanced out by the need to act in the individual’s best interests. The Confederation anticipates that the need to establish capacity for individual decisions will increase the number and frequency of applications, and is concerned that this will impact on the workload of health and social care professionals.

Advance Decision to refuse treatment

The NHS Confederation welcomes the inclusion of advance decisions within the Bill and believes it will provide clarity for healthcare professionals, carers and those involved in providing treatment. By requiring the decision to be validated the Bill also safeguards the individual and all concerned.

5. ARE THERE RELEVANT ISSUES NOT COVERED BY THE DRAFT BILL WHICH IT SHOULD HAVE ADDRESSED?

The Confederation is satisfied that the Bill addresses the relevant issues.

6. IN WHAT WAYS MIGHT THE DRAFT BILL BE IMPROVED?

The Bill successfully builds on the systems currently in place within the NHS for people lacking mental capacity—in terms of assessing capacity, applying the doctrine of best interests and invoking the Court of Protection. This provides real opportunity for the NHS (PCTs and mental health trusts, clinicians, advocacy services, the NHS university and other educational bodies, intermediate care teams, carers etc) to be key players in delivering the reforms. However the Bill also carries significant training implications for staff (clinicians and managers at all levels) working in the NHS and social services. This must be tackled through the Codes of Practice in order to ensure smooth implementation.

Relationship with the reform of the Mental Health Act

Part 5 of the draft Mental Health Bill published in June 2002 outlines informal treatment of patients not capable of consenting. This part of the draft Bill is intended to address the issues raised by so called “Bournewood” cases. The timetable for the parliamentary process of this proposed bill and indeed whether or not the draft Bill will be amended before the parliamentary stage is currently not known. In order to avoid confusion, it is clearly imperative that the two pieces of legislation are carefully scrutinised to ensure they are compatible and do not leave service users, carers or professional staff or the relevant statutory organisations confused or involved in bureaucratic and or legislative tangles.

The NHS Confederation would be happy to provide further information on any of the points raised above and looks forward to seeing the report of the Parliamentary Committee.

August 2003

101. Memorandum from the Catenian Association (MIB 831)

SUMMARY AND RECOMMENDATIONS

A. The present Bill goes further than the comparable legislation in Scotland (the Adults with Incapacity Scotland Act) by placing Advance Decisions on a statutory basis. Advance Decisions should not be given statutory force.

B. There is no clear duty of care placed upon the donees of Lasting Power of Attorney. The provision of a (criminal) sanction in the event of wilful neglect seems to us to afford insufficient protection for the incapacitated person especially with regards to the refusal of medical treatment, including the provision of food and fluids, which might bring about the death of the patient

C. There are insufficient safeguards for preventing financial abuse and conflicts of interest between attorney and patient. We propose that the attorneys, whilst maintaining their roles in financial and welfare matters, should not be empowered to make medical decisions. These should remain with health care professionals.

D. Nevertheless, the rights of attorneys should include the right to be consulted about treatment as a mark of good practice. The attorneys should therefore be statutory consultees rather than proxy-decision makers in health care matters. This would not only remove a heavy burden of personal and moral responsibility from attorneys, but maintain the current legal liability with health care professionals including the right of patients to due compensation for negligent medical management. If attorneys were to make health care decisions there should be a statutory duty of care on appeals procedures in the event of disputes. In cases of disagreement between doctor and attorney there should first be recourse to a second medical opinion procedure rather than to the courts, which would be time consuming, expensive and practically cumbersome.

E. The Bill should include a definition of basic medical and nursing care which cannot be refused by an attorney, court appointed deputy or advance decision. The definition of basic care should include the provision of food and fluids. Difficulties arise when treatment refusals are suicidal motivated or where they are made by attorneys with a financial conflict of interest. The Bill must make it clear that suicidal motivated refusals of treatment eg in the form of a suicide note forbidding resuscitation ought not to be followed and might involve aiding and abetting a suicide. The deliberate withdrawal of ordinary treatment such as insulin or the withholding of food and fluids must never be done with the purpose of bringing about the death of the patient. Any act or omission done with the intention of bringing about the death of a patient should remain unlawful.

DETAILED SUBMISSION

1. The Catenian Association is an association of practising Catholic business and professional men (including in particular many lawyers and doctors), most of whom are married and have families. Membership in the United Kingdom numbers about 9,500 and thus is one of the largest Catholic bodies in the country.

2. This submission will be restricted to those matters included in the draft Bill, which affect the Catholic viewpoint. The Bill as a whole codifies a substantial number of matters relating to those who suffer incapacity in relation to welfare and financial matters. It also clarifies the law for carers by introducing a statutory general authority to act reasonably in the best interests of the incapacitated. On the other hand, there are sections dealing with "advance decisions" and proxy-decision making which are of concern to us.

LASTING POWERS OF ATTORNEY

3. At present no-one can give legally binding consent on behalf of a mentally incapacitated adult patient in relation to health care or welfare matters. However, the contingent necessity to provide treatment and care for the incapacitated has been recognised in law as the "principle of necessity" following the case of *Re F* in 1990 and subsequently by several other cases. We are not convinced that there is a need for lasting powers of attorney in relation to health care matters because of the developments that have taken place in common law. Indeed, we see potential problems if they are placed on a statutory basis. The views of the next of kin or relative can be extremely useful to health care professionals and ought to be sought as a part of good medical practice.

4. However, problems arise when the attorney is not simply bearing witness to the would-be wishes of the patient but rather is making decisions on the attorney's own behalf. There can be no ethical justification for accepting the refusal of treatment of an attorney when there is reason to believe that the attorney's views do not reflect those of the patient or where there is a financial conflict of interest between patient and attorney or where the medical advisers know that medical treatment would be beneficial to the health of the patient. For example, a refusal of treatment by an attorney might lead to the death of a patient obviating the need for expensive residential or nursing home care and/or releasing the estate of the patient. There would clearly be a conflict of interests if the attorney were to be a beneficiary of the will of the patient. Since attorneys are likely to be appointed from among close relatives (especially children of the donor of the power) this is frequently going to be the case.

5. Decisions made by donees of Lasting Powers of Attorney (LPA) will cover financial, welfare and health care issues and will be wide-ranging. We do not believe that there are sufficient safeguards in the Bill to prevent financial abuses. Indeed, in the Commentary and Explanatory notes (p 45) it was pointed out that Master Lush, Master of the Court of Protection, in 1998 estimated that financial abuse may occur in as many as 10-15 per cent of EPA cases that are registered with the Public Guardianship Office.

6. The Bill would not prevent the donee of LPA from acting contrary to the medical best interests of the patient. The decision of the donee of LPA will override that of the doctor or relatives. "Subsection (2) clarifies that the general authority will be "trumped" by a decision of a donee of a lasting power of attorney or of a deputy." (Commentary and Explanatory notes p. 24). The donee of LPA does not have a specified duty of care. Therefore, the standards required of the attorney may fall below those of a doctor or nurse who are subject to claims in medical negligence. There is no provision for patients to receive compensation for wrongful decisions made by LPA attorneys that are contrary to good medical practice and judgement. The only safeguard for the patient is in the case of ill-treatment or wilful neglect which would be a criminal offence.

7. We therefore propose that the donee of a lasting power of attorney should act as a statutory consultee who ought to be consulted whenever medical decisions are made as a mark of good medical practice but should not be empowered to consent to or refuse treatment or care.

8. We believe that the duty of care in the management of incapacitated people would remain with health care professionals who ought to consult the patients' nearest relatives, carers and attorney as a matter of good practice. Involvement of the attorney should be regarded as evidence of acting reasonably under the circumstances. If attorneys are to be empowered to make medical decisions, they should be under a duty of care in civil law to the patient for wrongful decisions. In Scotland, according to the Regulation of the Adults with Incapacity Scotland Act (2000), welfare attorneys have a duty of care under common law. "An attorney, guardian or other person acting under the Act is held at common law to owe a duty of care to the adult with incapacity. They must act with due skill and care in exercising the power they have been given in relation to the adult".

9. There is no provision in the Bill for a second medical opinion procedure in the case of disputes between the attorney and doctor. In Scotland, disputes are first referred to a second opinion doctor. If they cannot be resolved then interested parties can apply to the Court of Session to determine if the treatment may proceed. There is no such provision in the current Bill in which disputes would be referred directly to the Court. If this is done we believe it would be time consuming and expensive.

“BEST INTERESTS”

10. Although there is a checklist of factors to which regard is to be had in considering the question of best interests (Clause 4 (2) of the Bill), this does not appear to us to be exhaustive or exclusive, for example, there is no mention of medical best interests. These interests, which are decided by the patient’s doctor, should be taken into account before health care decisions are taken. Such decisions should be made after assessing the condition and circumstances of a patient and in addition have regard to the other factors referred to in clause 4. We consider that it is essential for medical need to be taken into account before a patient’s “best interests” can be determined.

MEDICAL TREATMENT

11. The definition is wide and there is no consideration in the Bill of basic or nursing care. Basic care would include those things which are required in both health and disease to sustain life

- warmth, shelter, clothing, companionship, food and fluids and the provision of ordinary medical, nursing and palliative care. It should be unlawful to deny a patient basic care through an advance decision or a decision by an attorney or court appointed deputy.

ADVANCE DECISIONS

12. The validity and applicability of advance decisions has largely been defined by the case of *Re AK* which seems to us to be both practical and ethically acceptable. According to this case nothing should be done that is contrary to the known views of a patient when of sound mind provided that care is exercised to “ensure that such anticipatory declarations of wishes still represent the wishes of the patient. Care must be taken to investigate how long ago the expression of wishes was made. Care must be taken to investigate with what knowledge the expression of wishes was made. All the circumstances in which the expression of wishes was given will of course have to be investigated.” *Re: AK* (High Court of Justice, Family Division: Hughes J. (2000) 58 B.M.L.R. 151; [2001] 1 FLR 129)

13. We are concerned that the Bill would allow the withdrawal of life sustaining food and fluids from vulnerable incapacitated patients. Thus these sections seem to us to allow euthanasia, which is contrary to Government policy as we understand it and is equally contrary to the teaching of the Catholic Church. Paragraphs 2277 to 2279 of the Catechism of the Catholic Church are set out below:

Paragraph 2277 Whatever its motives and means, direct euthanasia consists in putting an end to the lives of handicapped, sick or dying persons. It is morally unacceptable.

Thus an act or omission which, of itself or by intention, causes death in order to eliminate suffering constitutes a murder gravely contrary to the dignity of the human person and to the respect due to the living God, his Creator. The error of judgment into which one can fall in good faith does not change the nature of this murderous act, which must always be forbidden and excluded.

Paragraph 2278 Discontinuing medical procedures that are burdensome, dangerous, extraordinary, or disproportionate to the expected outcome can be legitimate; it is the refusal of “over zealous” treatment. Here one does not will to cause death; one’s inability to impede it is merely accepted. The decisions should be made by the patient if he is competent and able or, if not, by those legally entitled to act for the patient, whose reasonable will and legitimate interests must always be respected.

Paragraph 2279 Even if death is thought imminent, the ordinary care owed to a sick person cannot be legitimately interrupted. The use of painkillers to alleviate the sufferings of the dying, even at the risk of shortening their days, can be morally in conformity with human dignity if death is not willed as either an end or a means, but only foreseen and tolerated as inevitable. Palliative care is a special form of disinterested charity. As such it should be encouraged.

14. These paragraphs, which conform fully with Article 2 of the European Convention on Human Rights (“Everyone’s life shall be protected by law. No-one shall be deprived of life intentionally”), highlight our concerns about the contents of this draft Bill. The Bill as it currently stands would permit the withdrawal of food and fluids with the result that patients would die. In our view this inhuman practice should be abolished in the Bill.

August 2003

102. Memorandum from Geneva Richardson, Professor of Public Law, Queen Mary, University of London (MIB 556)

1. Introduction: I have a longstanding interest in mental health law and in questions of mental incapacity. In 1998–99 I chaired an Expert Committee established to advise ministers within the Department of Health

on the reform of mental health legislation. In 2001 I visited Victoria and New South Wales in order to examine the relationship between mental health and adult guardianship legislation in two jurisdictions where parallel structures have existed for some years.

2. Scope of memorandum: I will restrict this memorandum to the relationship between the Mental Incapacity Bill (MI) and the current draft Mental Health Bill (MH) with regard to the provision of medical care and treatment. In very general terms it will address the last four themes described in the call for evidence, 17 July 2003. I appreciate that the government has not yet introduced its Mental Health Bill, but much of what is said below applies equally to the current Mental Health Act 1983.

3. The two bills: In relation to the provision of medical care and treatment both bills provide substitute decision-making structures. The relationship between the two is important because they cater for similar, though not identical, populations and there are significant differences in approach between the bills. MI provides for those who lack the capacity to make decisions, while MH covers people with mental disorder who require care and treatment for that mental disorder. Many, but not all, of those who fall within the possible remit of MH will lack decision-making capacity and could be covered by MI. Similarly many who lack capacity and fall within MI may need treatment for mental disorder and so could be covered by MH.

4. The main differences between the two bills which are significant here include:

- Capacity: MI applies only to those who lack capacity; MH does not require an absence of capacity;
- Best Interests: MI requires decisions to be made in P's best interests; MH has no such express requirement;
- Medical Treatment: MI deals with medical treatment for all conditions; MH covers only treatment for mental disorder;
- Resistance: MI allows care and treatment despite resistance in certain circumstances only; MH is specifically designed for cases of active non-compliance;
- Safeguards: MH contains more automatic safeguards for the patient;
- Advance Decisions: MI codifies the common law rules on advance decisions to refuse treatment; MH makes no mention of advance decisions.

5. Their areas of application: The possible areas of overlap between the two bills can be illustrated by using three distinctions: with capacity/without capacity, compliant/resisting, and physical/mental disorder. If these distinctions are applied the following pattern emerges:

- Resisting people with capacity needing treatment for mental disorder: MH only;
- Resisting people with capacity needing treatment for physical disorder: common law only, resistance must be respected;
- Compliant people without capacity needing treatment for mental disorder: primarily MI although MH Part V would apply where the person is resident in hospital;
- Compliant people without capacity needing treatment for physical disorder: MI only;
- Resisting people without capacity needing treatment for mental disorder: primarily MH although MI could apply;
- Resisting people without capacity needing treatment for physical disorder: MI only.

6. So where treatment is required for physical disorder and P lacks capacity MI must be used. Where treatment for mental disorder is required MH must be used if P has capacity and is refusing. Where P lacks capacity and requires treatment for mental disorder both MI and MH may be available, and the remaining paragraphs will consider the possible implications of the choice between these two structures.

7. Clause 27: the MI bill, clause 27, states that MI powers cannot be used to authorise treatment where that treatment "is regulated" by the Mental Health Act. On the face of it this appears to mean that where MH powers are in fact assumed MI will not apply and treatment decisions must be made under MH. There is, however, an alternative interpretation, that MI powers must not be used in any case where MH could potentially be applied. This second interpretation would have far reaching implications and would give rise to significant practical difficulties unless the coverage of MH powers were to be defined with absolute precision. It will therefore be assumed that the first interpretation will prevail and that there is nothing in clause 27 to require the use of MH in every case where it could potentially apply. For the removal of all doubt, however, it will be necessary to clarify the position before the bill is introduced.

8. The choice of structure: in theory it might be assumed, as in paragraph 5 above, that MI would be preferred in cases of compliance and MH in cases of resistance. Certainly when P lacks capacity and is resisting, Part 5 of the MH bill seems to imply that full MH regulation should be used. But since the MI bill, clause 7 and 10, would allow resistance to be overcome in certain circumstances, it appears that MI would be available in those circumstances despite P's resistance. Some clarification will be required here before these structures are finalised and the following points might be borne in mind.

9. From the point of view of the care providers the process of applying for MH powers might be regarded as cumbersome and, if P is already receiving care under MI, there might be every incentive to continue under that scheme. From P's point of view, on the other hand, there are advantages and disadvantages to both systems. Decisions taken under MI would have to be in P's best interests, not so under MH. But MH might

offer better automatic safeguards through the need for tribunal approval. Under MI there would be supervision by the Public Guardian (cl 48(1) (c) and (h)) but it seems unlikely that the Public Guardian will be sufficiently resourced to provide regular automatic supervision of all donees of lasting powers of attorney. In Victoria the absence of effective safeguards for those under guardianship was a common concern.

10. In addition the relevance attaching to advance decisions to refuse treatment must be considered. Under MI advance decisions, when valid and applicable, must be respected. Under MH there is no such provision and, since the refusal of treatment by a patient currently having capacity can be overridden under MH, there is no suggestion that a refusal made in advance will attract any more respect. This issue certainly requires clarification. It would obviously be possible for either MI or MH to change its position. But if, as seems more likely, both the MI provisions on, and the MH attitude towards advance decisions remain unaltered, then the decision to use MH rather than MI would deprive P of the benefit of any advance decision in relation to treatment for mental disorder. In such circumstances guidelines might have to be developed to govern the choice of structure. Unless such guidelines were to deny all significance to advance decisions in relation to treatment for mental disorder by recommending the invariable use of MH, they would have to recommend the use of MI in certain circumstances. Ironically, this could mean that a refusal of treatment made in advance would carry greater weight than a refusal made with capacity at the time.

11. Finally, when P is not resisting the presumption is likely to be that MI will be used unless P is in hospital, in which case Part 5 of the MH bill, as presently drafted, would be relevant. The use of MI rather than MH in these cases has advantages for carers and professionals and for P herself, but it raises again the question of safeguards. The non-resisting person who lacks capacity may be very severely disabled and hence peculiarly vulnerable. Such a person might be effectively “detained” either in his or her home or in some form of residential care, and might be subject to regular medication. Every effort must be made to ensure an adequate level of safeguard particularly when P is not resident in hospital. The position here may of course require revision subsequent to the awaited ECtHR decision in *Bournewood*.

12. In summary the position of those people who could potentially be covered by either bill needs extensive clarification. In particular attention needs to be paid to the precise meaning of clause 27, the relative advantages and disadvantages of both structures for all those concerned, and the significance of advance decisions.

August 2003

103. Memorandum from Age Concern (MIB 729)

SUMMARY

- As a member of the Making Decisions Alliance (MDA), Age Concern England fully endorses MDA’s submission. This separate submission underlines those concerns and raises some additional points.
- The publication of the Bill is welcomed, although there are aspects on which clarification and further consideration would be beneficial.
- The Bill should begin with the presumption against lack of capacity.
- Supported decision-making should be incorporated onto the face of the Bill; and advocacy also included.
- The principle of the person’s best interests should also pay attention to their past and present behaviours.
- A vital step—deciding that someone lacks capacity and communicating that decision—is missing from the Bill.
- The parameters of Lasting Power of Attorney (LPA) need clarifying, including how these are used at times when the donor has regained capacity; the minimum qualifying characteristics for LPAs and Deputies should be extended to include criminal convictions and care offences.
- Clear examples of what constitutes “day-to-day care” will be needed to ensure the general authority is not used to make substantial decisions.
- Further checks are suggested in respect of expenditure made by those exercising the general authority.
- Legislation covering capacity and incapacity should include appointeeship.
- Clarification is needed on the general relationship between the proposed Bill and the Data Protection Act 1998, and the relationship between the draft Bill and the No Secrets guidance.
- Guidance will be needed for LPAs and Court-appointed deputies, where more than one party is acting for an individual.
- Consideration should be given to mechanisms for “lodging” advance decisions and advance statements with health or social care bodies.

1. WAS THE CONSULTATION PROCESS PRECEDING THE PUBLICATION OF THE DRAFT BILL ADEQUATE AND EFFECTIVE?

1.1 Age Concern England believes that the consultation process preceding the draft Bill was adequate and effective. We are especially mindful of the number of years over which discussion has taken place since the publication by Age Concern of its book, *The Law and Vulnerable Elderly People* in 1986; the subsequent Law Commission inquiry, which reported in 1995; the response from government since 1997; and the number of helpful stakeholder meetings held with officials and the then Minister, Rosie Winterton MP. One important outcome of this approach is that opportunities to understand the complexities and subtleties of the issues have resulted in a draft Bill whose principles are warmly welcomed by Age Concern England.

2. ARE THE OBJECTIVES OF THE DRAFT BILL CLEAR AND APPROPRIATE?

2.1 The Bill is based on three key principles: that everyone should first be presumed to have capacity to make their own decisions; that a functional test of capacity should be applied for all decisions at the point when they need to be made; and that, where someone else makes a decision on behalf of another (because capacity has been assessed as lacking in respect of that particular decision), they must act in the best interests of the other person.

2.2 These are vital safeguards for older people and others. The pulling together of a variety of legal frameworks within which individuals are able to make their own decisions and have others act on their behalf, the extension of decision-making beyond matters of property and financial affairs, and the creation of a new Court of Protection with enhanced duties and responsibilities, are also appropriate.

3. DOES THE DRAFT BILL MEET THOSE OBJECTIVES ADEQUATELY?

3.1 Age Concern England believes there are some changes from which the draft Bill would benefit. We believe that the Bill itself should begin with the presumption against lack of capacity. This could be easily achieved by renumbering existing Clause 3 as Clause 1. We feel that this would send an important message to everyone affected by the proposed changes, that the starting point is always that the person has capacity.

3.2 Clause 2 (3) is one of the most important objectives of the Bill, we believe, although we would ask that it be amended to read “all practicable steps to support him to do so”. This would create the notion of supported decision-making on the face of the Bill, an essential element in our view if professional and lay audiences are fully to comprehend how individuals whose capacity may fluctuate, or who may be able to take some decisions but not others, are able to arrive at their particular decisions.

3.3 Clause 2 (3) also allows for the possibility of advocacy support, but it is a great disappointment that this is not specifically mentioned in the Bill. Reliance on the Mental Health Bill in this respect would, we believe, be inappropriate since access to independent advocacy is only proposed for those who have been compulsorily detained. As such it would not, for example, be relevant to the hundreds of thousands of older adults who ordinarily live in care homes. Access to independent advocacy will also prove particularly important in respect of the use of the general authority (Clause 6) to ensure that the checks and balances envisaged by the proposed strengthened Court of Protection are in place at all levels and at all stages of the decision-making process. As legislation entitling people with disabilities to advocacy already exists on the statute books (Disabled Persons (Services, Consultation and Representation) Act 1986), this draft Bill provides an ideal way for it to be enacted.

3.4 We believe that the principle of the person’s best interests (Clause 4) would be further enhanced by the addition to “as to his past and present wishes and feelings” (Clause 4(2)(c)(i)) of the phrase “and behaviours”. We feel this would be of great help in matters of culture, sexuality and religion (and other beliefs); and also recognise that much decision-making is naturally of a progressive or cumulative nature in which behaviour as well as feelings is an important aspect.

3.5 The principle and the process whereby someone has decided another person lacks capacity in respect of any decision would benefit from some further reflection. At present, it appears there is a gap in the draft Bill between how to decide that someone lacks capacity, and the need to then act in their best interests—this missing element concerns how the decision is made and communicated.

3.6 One aspect to the draft Bill that is unclear concerns its remit in terms of the aspects of life about which decisions can be made in the various frameworks described. Clauses 17 and 18 set out the powers relating to personal welfare, and to property and financial affairs but appear as “stand-alone” powers except in relation to the restrictions on these areas established in Clause 20 for Court-appointed deputies. Clauses 23-25 set out the parameters relating to the following of a person’s advance decisions(s); and Clause 26 sets out specific exclusions relating to decisions about family and other relationships. Clearer links need to be made between Clauses 17 and 18 and the role of Lasting Powers of Attorney (LPAs); and between those clauses creating the powers of LPAs, Court-appointed deputies and the general authority, and Clauses 17 and 18.

3.7 We would also appreciate clarification as to whether proposals under the personal welfare LPA will mean that donors retain, at times when they have capacity, decision-making over only health matters, or whether this will also include broader personal welfare matters.

3.8 In respect of the general authority, there will need to be very clear examples of what does, and does not, constitute an everyday form of care or a decision about day-to-day care. There are particular concerns that without clear guidance, substantial decisions (such as moving permanently to live in a care home) may be taken under the general authority. Information will be needed (especially by carers) in order to make clear the parameters to, and responsibilities of, acting under the general authority. In addition, if expenditure is regularly incurred for the same form of care, we also feel that those exercising the general authority should be obliged to bring this to the attention of the proposed Court of Protection.

4. ARE THE PROPOSALS IN THE DRAFT BILL WORKABLE AND SUFFICIENT?

4.1 One of the most important aspects of the draft Bill lies in the proposal to establish a Lasting Power of Attorney (LPA), to replace existing Enduring Power of Attorney (EPA) arrangements. This is particularly welcome as it overcomes current difficulties whereby whilst an EPA may make financial decisions they are unable to take welfare decisions on behalf of the other party: in reality, for many older people, decisions about health and welfare (such as moving to live in a care home) are inextricably linked with decisions about spending money (such as paying care home fees).

4.2 However, there are other common arrangements that involve the handling of individual older people's state benefits, through the offices of the Department for Work and Pensions (DWP), particularly that of appointees. Detailed comments on this point are included in the submission from MDA. There are particular concerns for older people that, for those whose only income is via benefits (ie those pensioners who do not have an occupational pension) appointees have control over the whole income if the person has been assessed, on the current "one-off" occasion by DWP staff, as being mentally incapable of managing their financial affairs. This system does not accord with the principles of the draft Bill. Nor does it give older people protection as there are few checks made by the DWP on appointees.

4.3 Age Concern believes that any legislation covering capacity and incapacity should extend to appointeeship. At the very least, appointees should be required to act within the principles of the draft Bill with regards to decisions about capacity and acting in the person's best interests, and these changes reflected within social security legislation. It would also need to be made clear how the appointee role would stand in relation to the general authority. In our view, appointeeship would best be absorbed by Court-appointed deputies using a similar process to the current "short order" which is used when a person's finances are such that full receivership is not required.

4.4 Given that, on the financial side, the proposed LPA arrangements mean that the donee could act on the donor's behalf even if they have capacity, further consideration needs to be given to how banks and other financial institutions would be certain whether a donee was acting when someone lacked capacity or not. This is important as it reflects the practical application of one of the LPA's most attractive attributes, namely that it is not assumed that once an LPA has been registered that the person would permanently lack all decision-making capacity from that point onwards (with current EPA arrangements, registration has tended always to mark the point beyond which permanent and total incapacity is assumed). This matter will require some further thought to preserve, in practice, this important principle, whilst at the same time ensuring that banking practice is able to go some way to protecting individuals against financial abuse.

4.5 For holders of both LPAs, and Court-appointed deputies, we believe that the same minimum qualifying characteristics should apply, but that these should be extended beyond bankruptcy, to include criminal convictions and care offences.

4.6 Any Codes of Practice and guidance should both be followed as a requirement. Much of the detail of the proposals—for example, checklists for "best interests", and definitions of terms such as "substantial risk of significant harm"—are to be contained in such Codes and associated guidance. We believe that Section 30 (7) (b) be amended so that these Codes must be taken into account by the court.

4.7 The relationship between those exercising the general authority and their access to an individual's money would benefit from further strengthening of checks and balances. We suggest that Section 31 contains an additional sub-clause of undue influence in relation to the general authority and the handing over of monies for purchases made. We also suggest a financial limit be set under the general authority (whether for single or cumulative reimbursements), above which anyone using that authority in that way would be required to notify the Court of Protection.

4.8 We note that, in the regulatory impact document, mention is made of an increase in legal help. We believe that legal aid should be made available where the disputes that are going to the Court are significant to that individual, such as a dispute about whether the person lacks capacity to make an important life-changing decision. Some parameters could be drawn up for these situations. For others seeking the Court's decision legal aid should also be available, on the usual means-tested basis.

5. MIGHT LESSONS BE LEARNED FROM SIMILAR LEGISLATION ALREADY IMPLEMENTED IN SCOTLAND AND ELSEWHERE?

5.1 One of the changes in Scotland, brought about through the Adults with Incapacity (Scotland) Act 2000, concerns authorisation for carers and other individuals (but not social work staff) to obtain authority to access the funds of an adult in order to meet living expenses. Authority is granted by the Public Guardian and can last for up to three years at the first application (although this may become indefinite when renewed). It involves the Public Guardian authorising how much money may be transferred from the adult's account to a designated account, and gives a certificate to whoever is allowed to open and access the designated account. It can be used for day-to-day living expenses and for paying regular bills. Age Concern England suggests this system be further considered as one way of dealing with concerns about those who, under the proposed general authority, would be regularly accessing another's finances to deal with daily expenses.

6. ARE THERE RELEVANT ISSUES NOT COVERED BY THE DRAFT BILL THAT IT SHOULD HAVE ADDRESSED?

6.1 It should be made clear what powers LPAs and Court-appointed deputies will have to access any relevant information to assist them in their decision making, particularly copies of care plans and health records; and the general relationship between the proposed Bill and the Data Protection Act 1998.

6.2 The relationship between the draft Bill and the Protection of Vulnerable Adults (PoVA) guidance (as set out in No Secrets) to local authorities needs to be made clear. In particular, we would welcome a strong relationship between the Court of Protection and local authorities in terms of sharing concerns about individuals believed to be at risk of abuse.

6.3 We understand that, under the draft Bill, it will be possible for at least two people separately to hold, for the same individual, an LPA covering health and welfare decisions and an LPA covering property and financial affairs (this also applies to Court-appointed deputies). Clear guidance will be needed, to both LPAs and Court-appointed deputies, as to how they should work together where necessary in such situations.

6.4 We believe consideration should be given for mechanisms for "lodging" or otherwise recording advance decisions and advance statements with health or social care bodies (for example, with a person's GP records). This should help both to militate against individuals seeking to hide the existence of others' advance decisions, and assist in considerations of "best interests" by having available advance statements.

6.5 We believe that Court-appointed deputies should be required to follow the same requirements set out for LPA donees with regards to the limits on their abilities to ignore advance decisions to refuse treatment.

6.6 Finally, we understand there may be some concerns that the draft Bill does not include matters of decision-making as it relates to taking part in research. Should the Joint Committee decide to move on this point, we would ask that a distinction be drawn between taking part in medical or clinical research, and that of user and carer consultation and involvement through which individuals' personal views and experiences are sought.

August 2003

104. Memorandum from the Alzheimer's Society (MIB 783)

EXECUTIVE SUMMARY

The Alzheimer's Society welcomes the publication of the draft Bill which has received widespread support from members. People with dementia and their carers have campaigned for new legislation for over a decade. This Memorandum documents their experiences and powerfully highlights the urgent need for reform. The Alzheimer's Society is a member of the Making Decisions Alliance and has contributed to its submission to the Committee.

People with dementia represent the largest single group of adults affected by incapacity. The Society welcomes the draft Bill's proposals to put into law the principle that all adults are assumed to have capacity to make decisions for themselves. This is vital for people with a diagnosis of dementia who are currently often wrongly assumed to be incapable of making decisions.

The new Bill promises to give people with dementia more control over issues such as the treatment they receive, how they spend their money and where and how they live. It will also allow them to plan for the future and choose who they would like to make day-to-day decisions on their behalf when they are no longer able to do so. Advance directives will give people assurance that their wishes about end of life treatment will be respected. The Society proposes that the Bill:

- is named the Mental Capacity Bill to reflect the presumption of capacity enshrined in the Bill
- includes detail on how capacity will be assessed, and by whom

- includes a legal right to access independent advocacy at particular points in the assessment process
- includes explicit restrictions on the use of general authority to act
- recognises advance statements
- requires deputies to comply with a valid advance directive
- sets out an appeal mechanism by which people can challenge an assessment
- allows people to nominate a research proxy or attorney
- refers to “personal best interests” rather than “best interests.”

The Society believes that many people with dementia and their carers will not benefit from new legislation unless early diagnosis improves. The effective implementation of the draft Bill depends on significant investment in public and professional education/awareness raising.

1. THE ALZHEIMER’S SOCIETY

1.1 The Alzheimer’s Society is the leading care and research charity for people with dementia and their carers. It was founded in 1979 as the Alzheimer’s Disease Society. It is a national membership organisation, with over 25,000 members and operates through a partnership between over 250 branches and support groups and the national organisation in England, Wales and Northern Ireland.

1.2 The Society has expertise in information and education for people with dementia, their carers and professionals. It provides helplines and support, runs quality day and home care, funds medical and scientific research and gives financial help to families in need. It campaigns for improved health and social services and greater public understanding of all aspects of dementia.

1.3 People with dementia represent the largest single group of adults affected by incapacity. There are over 700,000 people with dementia in the UK. Dementia affects one person in 20 aged over 65 and one person in five as they reach over 80 years of age in the UK. As the population ages so the number of people with dementia will grow. There are also over 18,000 people with dementia aged under 65 years of age in the UK.

1.4 People with dementia lose capacity over time. Alzheimer’s disease is the most common form of dementia and the rate at which a person deteriorates will vary from individual to individual. With earlier diagnosis and new treatments, people are retaining capacity for longer. They are also living longer with dementia and increasing numbers of people are now living with dementia for 20 years. Carers continue to undertake most of the caring for people with dementia and this draft Bill has important implications for both people with dementia, their carers as well as a range of professionals.

1.5 The Alzheimer’s Society has been campaigning for new legislation on mental capacity for over a decade and welcomes the introduction of the draft Bill. The Society has been a core member of the Making Decisions Alliance and has contributed to its submission to the Committee.

1.6 The Society decided to co-ordinate responses from its members rather than ask them to write individually to the Committee. There is huge support for this legislation.

2. WAS THE CONSULTATION PROCESS PRECEDING THE PUBLICATION OF THE DRAFT BILL ADEQUATE AND EFFECTIVE?

2.1 Yes. The Alzheimer’s Society has had the opportunity to input into policy in this area over a number of years and believes that this has resulted in a draft Bill which will help to improve the lives of millions. The Society is very concerned that there is no further delay to the implementation of this urgently needed legislation.

2.2 The Society has undertaken extensive consultation with its members, through its website, publications and through regional meetings. It is the words and experiences of people with dementia and their carers that have helped to inform this memorandum.

3. ARE THE OBJECTIVES OF THE DRAFT BILL CLEAR AND APPROPRIATE?

3.1 Yes. The draft Bill sets out new powers which would support and protect people with dementia. In particular, these objectives would:

- confirm the importance of presuming each individual has capacity until proven otherwise
- support a person with dementia to make as many of their own decisions as possible
- give carers more rights in day to day decision making on behalf of someone with dementia who does not have capacity
- allow a person with dementia to choose who they would like to make decisions for them when they are no longer able to do so

- enable people with dementia, while they have capacity, to make an advance directive which they know will be legally binding
- protect more people with dementia without capacity from abuse and neglect.

4. DOES THE DRAFT BILL MEET THESE OBJECTIVES ADEQUATELY AND ARE THE PROPOSALS WORKABLE?

4.1 The presumption of capacity

4.1.1 The draft Bill highlights the importance of presuming that an individual has capacity. It is one of the underpinning principles that threads its way throughout the document. As such, it deserves to be given a higher priority and should be set out in Clause 1 of the Bill. Moreover, the title of the draft Bill, the Mental Incapacity Bill, undermines this principle. The Alzheimer's Society believes that the Bill should be known as the Mental Capacity Bill. This would help to emphasise the importance of assuming capacity, rather than incapacity.

4.2 Maximising decision-making

4.2.1 The Alzheimer's Society supports a decision-specific functional test of capacity which focuses on what a person can do rather than on what they cannot.

4.2.2 The draft Bill introduces a new definition of capacity which can only help to empower a person with a diagnosis of dementia. The Alzheimer's Society supports this functional definition of capacity which allows for variation over time and place, as well as according to the type of decision to be made. As one carer explained "there are degrees of capacity—incapacity does not happen overnight. "A person with a diagnosis of dementia is often assumed to have little or nothing to contribute—to have lost their faculties and their judgement. The use of terms such as "living death" and "the loss of self" reinforce negative images of people with dementia and do little to help foster the notion that they will have different levels of capacity to make their own decisions and plan for the future.

4.2.3 The need for a functional test of capacity is underpinned by comments made by members. Many reported that "people generally assume that dementia patients can't make decisions for themselves" while others wrote of their own mistaken assumptions:

"I made the mistake of assuming my husband couldn't make decisions for himself. A sharp telling off from him that he 'wasn't completely gaga yet' made me think again. Being involved in decision making rather than just doing as I suggest has made a great deal of difference to his capability. His mind seems to be growing by doing rather than degenerating."

4.2.4 Much good practice does exist and the introduction of new mental capacity legislation would bring an important practical and cultural shift. While some professionals reported that every effort was made to involve a person with dementia, others confirmed the need for greater attention to be paid to this area:

"My experience is that the professionals make the decisions. Very little effort is made to include a person with dementia and often only a token gesture. There needs to be criteria in place to ensure specific efforts are made and recorded."

"Assumptions are usually made that people with dementia cannot make decisions and are routinely excluded from the decision-making process."

4.2.5 While the functional definition of capacity is clearly explained, very little is said on how capacity will be assessed, when, and by whom. Although the Code of Practice will include the detail on assessment, being told that you do not have capacity to make your own decisions removes such a fundamental right that greater safeguards must be in place and included on the face of the Bill. Further detail on how capacity will be assessed, and by whom, needs to be included.

4.2.6 As one carer explained "unfortunately, there is not one single capacity assessment that will fit all purposes and all people." There is much good practice around assessment and the draft Bill codifies this. Several members reported excellent experiences of skilled, sensitive, multi-disciplinary assessment:

"The best and most helpful indication we have had of how incapacity is assessed is from our clinical psychologist in her five one hours sessions with my wife. Our GP, occupational therapist, admiral nurse and Alzheimer's Society staff have all directly or indirectly contributed to assessment of my wife's mental incapacity mostly by simple questions in discussion. It will be most important for the method and content of the Code of Practice of the 'final assessment' to be fully explained to the patient and carer."

4.2.7 However, others spoke of a battle to get a proper assessment. Previously, many health professionals dismissed dementia as "old age" and people were all too frequently told that nothing could be done. This experience was highlighted by one carer who said: "It was three years before our GP accepted that it was more than 'just getting old' and then we were referred to the psychogeriatric consultant. Obviously by that time it was too late."

4.2.8 The Audit Commission's recent research reinforces such a view. Over 1,000 GPs replied to their survey. Only about half of them believed that it was important to look for early signs of dementia or to diagnose early and less than half felt that they had received sufficient training for dementia. Many said that they saw no point in looking for an incurable condition.⁴¹ Early diagnosis and assessment allows people with dementia and their carers access to social and health care interventions.

4.2.9 Unless early diagnosis of dementia improves, people will be denied opportunity to make plans for their future. Several members commented on how rapid the decline was: "my husband had a series of mini strokes and was soon unable to speak or sign his name." Others were relieved to have managed to get the EPA signed just in time.

4.2.10 Clause 2(3) states that a person should not be "treated as unable to make decisions unless all practicable steps to help him do so have been taken without success." It is important not to underestimate the current situation in which many people with dementia still do not even get told their own diagnosis, let alone involved in decisions about their care.

4.2.11 The Society believes that an independent advocate can play an essential role in the assessment of someone's capacity and help to ensure that all steps have been taken before an individual is assessed as not having capacity. In particular, advocacy should be made available at particular "crunch points" to ensure that a person is supported to make as many of their own decisions as possible. These include major life changing decisions such as where someone lives or the appointment of a deputy. It is essential that people with dementia are not excluded from decision-making through a lack of expertise or resources. One member reported that she had been "assured that if staffing levels were improved then more effort would be made to include people with dementia in decisions."

4.2.12 Some members highlighted their concern over the use of cognitive function scores being used as a test for capacity. The reliance on the use of one particular test, the mini mental state examination, to assess capacity stems from its new use as an assessment tool in the prescription of the drugs for the treatment of dementia:

"Assessment is made regarding the prescription of drugs but this is repetitive and not a complete assessment of how I am."

"My wife was assessed originally by mini mental state examination. She failed badly but was still able to socialise and interrelate with people."

4.2.13 In addition, the Alzheimer's Society believes that there should be a mechanism for an individual to challenge a decision about their capacity in the draft Bill and they should be made fully aware of this right.

4.3 Allowing a person to choose who they would like to make decisions for them when they are no longer able to do so.

4.3.1 The Alzheimer's Society strongly supports the proposal to extend the current Enduring Power of Attorney (EPA) for financial affairs to a Lasting Power of Attorney (LPA) to include financial, health and personal welfare. Members endorsed these proposals wholeheartedly:

"I shall use the LPA as soon as it becomes available. Presumably it will supersede the EPA that I have already given to a couple of younger cousins."

4.3.2 Many people who are given a diagnosis of dementia at an early stage are relieved to have had an opportunity to put their affairs in order and plan for the future. One carer wrote that "my husband signed an EPA, witnessed by the doctor, while he still understood what he was doing—and he seemed relieved to have done so. I registered it later when the need arose and this worked well for us." The introduction of LPAs strengthens the rights of people with dementia to make plans for their future and gives them greater choice. It also introduces a degree of protection as well as reassurance that their wishes will be followed as far as is possible.

4.3.3 The need for health/welfare attorneys is apparent. Carers are often hindered in their caring role because they are not consulted or involved in important decisions about someone with dementia who has lost capacity. For example, one carer wrote "as my mother's main carer, I needed to know about her medication and any changes in dosage. But they wouldn't tell me because my mother couldn't consent to it."

4.3.4 The draft Bill includes proposals for new safeguards to protect the person making an LPA from abuse. The Alzheimer's Society supports the safeguards that both the donor and donee have to sign the document and are both notified on application and registration. The Society believes that this is an improvement on the current system operating with EPAs. Although the proposals also retain a welcome element of choice the flexibility also allows for the potential of abuse. For example, it is up to the donee to decide who needs to be informed about the creation of the LPA. The Society recommends that the LPA is signed by a third person other than the donor and the donee.

4.3.5 A person can only make an LPA while they still have capacity. The draft Bill also proposes that a person obtains a certificate to prove that they have capacity to make an LPA. On consultation, the need for a certificate of capacity prompted very varied responses from members. There was little consensus over how to balance the need for protection and a reduction in bureaucracy. Many carers felt that the need for a

⁴¹ Audit Commission, 2000, *Forget me not: mental health services for older people*, London: 21.

“certificate of capacity” went against a presumption of capacity which is enshrined in the draft Bill. Others felt that it was another barrier and would discourage people from making an LPA. However, most erred on the side of caution and the Society agrees that additional safeguards are necessary. As one carer stated “bureaucracy is awful, but the kind of abuse involved in these situations is sometimes worse.” Another wrote “that I am afraid we now live in a world where people need more protection—even at times, within their own family.”

4.3.6 Several members were concerned that a capacity certificate would deter many people in making an LPA, particularly those who were not middle class. For example, one member wrote: “All very well for middle class people who are acquainted socially with doctors and solicitors but a big obstacle for low income groups.” Others remained concerned about the ability of doctors and solicitors to really know the person well enough to confirm a statement of capacity. The Society would welcome further consideration of the use of a “springing clause” where the individual making the LPA chooses who should decide that they no longer have capacity—in most cases this is most likely to be someone who knows the individual well.

4.3.7 The Alzheimer’s Society recommends that a similar mechanism to obtaining a passport is used, thereby keeping it as accessible and affordable as possible. This would mean that a broader range of people in the community could sign the document to say that they believed the person had capacity to make an LPA. The Society is anxious that people are not required to pay for an additional fee for a “certificate of capacity”, for example from their GP.

4.3.8 The Society supports the proposal that a person may choose to hand over responsibility early for financial affairs while they still have capacity. Indeed, this is a provision, that many people currently choose to take up under the EPA system. However, a person acting as an attorney will not be able to make welfare or health decisions while an individual still has capacity. This is correct for any healthcare decisions, but the Society believes that some people will wish to hand over some personal welfare decisions early. Indeed, on consultation many members supported this move:

“I see no reason why the LPA should not be registered early provided that any decision can be overridden by the patient while they still have the mental capacity to do so.”

“It should be possible to register the document while an individual still has capacity if that is the wish of the individual, as with the existing EPA, to stipulate that it should not be registered, or that the donee should not act until incapacity is proven. A similar condition could also be written in about personal welfare.”

4.3.9 Moreover, the proposals in the draft Bill on LPAs differ on this issue from those on the Continuing Power of Attorney (CPA) proposed in Making Decisions. It was proposed initially that it would be possible for the attorney to exercise powers in relation to financial and welfare issues—but not healthcare—while the donor is still capable, if that was the donor’s wish. The Society would welcome further clarity on the change in this position and whether it really is workable and in the best interests of the person with dementia. It is important to note that, in practice, decisions about care often relate to both financial matters and personal welfare. It is difficult to separate financial decisions and welfare ones when it comes to moving a person to a care home for example.

4.3.10 At the moment, with the current system of EPAs many carers act as an attorney without actually registering it. Simply by signing the form they believe that they have a right to make decisions. This is currently not the case and is not envisaged for the proposed LPA. This, the Society believes is right. The donor should be able to choose when to register the LPA if they are aware that their powers are failing. However, many people will not have the insight to do this, leaving it to friends and family members nominated to decide when the right time to register the LPA is. This can be a very difficult decision:

“99.9 per cent of the time my wife has no idea what is going on but very rarely she knows exactly what she wants and is utterly logical. Can we ignore that 0.01 per cent?”

4.3.11 Careful guidance will be required to ensure that those acting as attorneys are supported to enable the donee to make as many of their own decisions as they would wish. While the majority of people with dementia progressively lose capacity, many will have fluctuating levels of capacity during the early stages. It is important that the mechanisms are put in place which are affordable and flexible enough to cater for this group.

4.3.12 Although reduced rates are available, a person with dementia currently has to pay £220 to register their EPA. On consultation, very few thought that this was a reasonable cost, most thought it was excessive (“especially once solicitors’ fees were added”, “£220 is over two-weeks pension”, “this is a further tax on the elderly and disabled”). Many members felt that this fee would dissuade people from registering an LPA and increase a person’s vulnerability to abuse.

4.3.13 One final point on LPAs relates to the language used. The terminology of donees and donor is confusing and runs contrary to the Wolfe reforms. The Society recommends that the use of donor and attorney is more accessible.

4.4 Rights to make day-to-day decision by carers

4.4.1 Dementia is a progressive, degenerative condition and one in which a person steadily loses capacity to make their own decisions. The Alzheimer’s Society welcomes the move to give carers legal powers to act on behalf of a person with dementia who does not have capacity. This would plug a significant gap in current

legislation. Moreover, the failure to involve carers, who currently undertake most of the care of people with dementia, often leads to poor quality dementia care. For example, one carer reported that “staff acted as if they had sole responsibility for my mother and knew exactly what she wanted without consulting us when they didn’t even know her name properly.” Another stated simply that “I have never felt that I was fully involved in decisions.”

4.4.2 Most carers of people with dementia are partners and often frail themselves. Two-thirds of people with dementia continue to live in their own homes. This includes a significant minority who live on their own, but most people with dementia are cared for by family members. Many recognise the huge responsibility of acting on someone else’s behalf—and often feel unsupported in their role. In addition, carers often feel very disempowered when trying to advocate for a person with dementia. The new general authority to act will help carers feel that they (a) have a right to be involved in decision making and (b) have a duty to be consulted. Currently, many carers do not feel able or entitled to speak out. It is hoped that the general authority to act will empower carers with new rights and give them increased confidence to act in the best interests of the person without capacity.

4.4.3 The draft Bill proposes that both carers and professionals will have an equal general authority to act in the best interests of the person with dementia. The introduction of the general authority raises new issues in relation to the different levels of duty placed on professionals and carers—all of whom will have a general authority to act. As one carer highlighted:

“Legislation must bear in mind that the vast majority of carers are likely to be non-professionals, with foibles, problems and a life of their own to live. In my experience the job is 24 hours a day, seven days a week, 52 weeks a year with no financial reward; just the satisfaction of doing their duty by their loved ones and making their lives throughout this dreadful and prolonged period, as comfortable as they can; doing for them as they would wish to be done by themselves.”

4.4.4 The Alzheimer’s Society would welcome further clarification on how the general authority to act will work in practice. What support will be available to help carers and professionals use this authority appropriately? Professionals have experience of, and are accustomed to, working to a code of practice. But little is known about how a separate code of practice will apply to carers. Further debate on this is necessary.

4.4.5 The draft Bill, for example, makes no distinction between a decision made by a carer or a professional—both of whom believe they are acting in a person’s best interests. And as one Alzheimer’s Society branch explained, decision-making works well “provided the family and friends agree with professionals about what’s best.” The Alzheimer’s Helpline receives hundreds of calls from carers every year who feel that they are unable to argue against professionals. Several carers felt strongly that “professionals alone should not have the right to make decisions without the involvement of a wholly independent adviser”.

4.4.6 The Alzheimer’s Society believes that independent advocacy would help to ensure that the best interests of the individual are at the forefront of decision-making as well as reduce the need to resort to court for the resolution of conflict between carers and health and social care professionals, particularly for common disputes such as moving someone to a care home.

4.4.7 Where shared decision-making can’t be reached, disputes can be referred to the court for resolution. A person wanting to act on behalf of a person with dementia without capacity can also apply to the court for a single order. This area also represents another example of where advocacy could play an important role and reduce the need for protracted and expensive court intervention.

4.4.8 In addition, the Society believes that the general authority confers too broad a power and restrictions should be placed on its use. Following consultation, members felt strongly that the following acts should not be permitted by someone with only a general authority to act:

- medical treatment
- moving someone, for example into a care home
- selling property
- managing financial affairs over a prescribed limit.

4.4.9 To avoid abuse the Bill should outline carefully what powers are conferred by a general authority to act. For example, people with dementia in care homes represent one particularly vulnerable group—especially those who have no visitors. While three-quarters of residents in care homes have dementia, most care staff have little training or understanding of dementia. The Society is concerned about the use, and monitoring, of the general authority to act.

4.4.10 This would mean that if decisions have to be taken that fall outside of everyday decisions, such as the giving of medication or the payment of bills, neither the carer or the professional alone could make a decision. This would help to improve the quality of life for many people with dementia and help to identify their best interests.

4.4.11 It is anticipated that joint discussion and decision-making would identify the best interests of the person with dementia and lead to prompt medical attention where appropriate. One of the problems of the current situation is that professionals are often reluctant to act when an individual cannot give consent, for example:

“My mother had dementia and very bad cataracts. Vision would have improved her quality of life enormously but the doctors refused to operate because we couldn’t agree on her behalf and she certainly couldn’t.”

4.4.12 There will be a great need for public education around the general authority to act. One member accurately identified one of the significant problems surrounding general authority when she asked “will there be an exhaustive list of the ‘everyday decisions’”?

4.4.13 The Society recommends that the principle of best interests is amended to “personal best interests.” This will ensure that the person without capacity is protected. For example, a person with dementia in a care home who is up all night may be given neuroleptic drugs to sedate them. This action might be in the best interests of other residents and of the staff, but is unlikely to be in the best interests of the person with dementia. However, as one carer highlighted, the provision of care, and an assessment of best interests is often dictated by costs:

“My aunt ‘wishes’ to have more than one bath per week but there are insufficient staff to grant those wishes although the home owners said she should have more and she pays a fortune to be there. My mother could not swallow biscuits and ‘wished’ for a piece of cake—but the home owner said cake was too expensive.”

4.5 Advance directives

4.5.1 The Society welcomes the inclusion of advance directives in the draft Bill. An advance directive enables a person with dementia to project their informed consent into a situation when they are no longer able to give it, thereby protecting their right to personal autonomy and choice and giving directions to carers and professionals about making decisions about treatment in advance of incapacity.

4.5.2 An advance directive gives people assurance that their wishes will be respected. It is also a tool which requires you to speak to others about your wishes. Several members reflected that for many this may not be feasible:

“I haven’t made an advance directive. I don’t want to think about the later stages of dementia—I am living for the present.”

“I find it almost impossible to get my wife to think about the future—some professional counsel may be required. A suitable checklist would make this easier.”

4.5.3 But as several carers highlighted, an advance directive can play an important role in making one’s views known:

“I intend to make an advance directive, having recently been involved with a situation where the family’s preferences were directly opposed to those of the consultant with no real means of knowing what the lady would really have wanted.”

“I approve of this concept of an advance directive. At one stage I had to decide whether or not my wife should be force fed. Following a family consultation with the pros involved, two of my three children agreed with my decision not to do so, but for a long time there was friction between me and the daughter who did not agree.”

4.5.4 Although advance directives are binding under common law they are not widely known about or easily accessed. One carer, as part of a research study on the ethics of dementia care, when asked about advance directives said:

“I think it would take an enormous responsibility for decision making off my children in my case. In fact we asked our solicitor in 1993 if he would help my husband to draw up an advance directive and he refused.”

The Society has long supported the use of advance directives and issued its own advance directive in September 2003 (appendix one). The Bill would make advance directives binding under statute law and provide people with dementia with precision about how they would work.

4.5.5 The inclusion of advance directives in the draft Bill will help reduce the misunderstanding and confusion which surrounds them. On consultation with members, several expressed concern about the use of advance directives. High levels of confusion exist with many believing that it is the same thing as euthanasia or assisted suicide. The Alzheimer’s Society believes that it is important to establish that an advance directive is entirely distinct from the promotion of euthanasia. Refusal of medical treatment at the end of life is distinct from a positive action to end life.

4.5.6 People with dementia in the late stages often experience great difficulty with swallowing. When this occurs in the final stages of the illness, most people accept that this is a part of the dying process and the most appropriate response is palliative care. The goal of dementia care at this stage is therefore one of comfort and emotional wellbeing—not of prolonging life. The Society believes that a feeding tube is rarely a source of

comfort at this stage of a terminal illness and that it is inappropriate for a person with advanced dementia to be given artificial hydration and nutrition for the sole purpose of prolonging life. In the advanced stages of dementia, quality of life rather than length of life should be prioritised.

4.5.7 The Society has serious concerns about the frequency with which people in the terminal stages of dementia are artificially fed and hydrated by a tube. The Society advocates that when a person is no longer able to eat, or is taking little or no fluids by mouth, the best way to alleviate the pain and distress of a person in the final stages of dementia is through one-to-one nursing. Family members, carers and nursing staff who sit by the bedside of a person with advanced dementia can provide appropriate quality care. A carer can offer sips of water or moisten a person's mouth and thereby provide a more appropriate and less invasive alternative to artificial hydration. The use of a tube for artificial hydration and feeding should not be considered best practice in the provision of care of people in the advanced stages of dementia.

4.5.8 An advance directive cannot authorise a doctor to do anything unlawful, such as practise euthanasia or act against their clinical judgment. The Society recommends that an advance directive should not authorise a refusal of "basic care" such as the maintenance of bodily cleanliness, alleviation of severe pain and the provision of direct oral nutrition and hydration.

4.5.9 The Society believes that advance directives should be regularly reviewed while the person still has capacity, and written following full consultation between a patient and doctor. It is important that they are as contemporary as possible.

4.6 Protection of people with dementia without capacity

4.6.1 The Society supports the creation of both the revised Court of Protection and the Public Guardian. These will help to protect some of the most vulnerable members of society. It is essential that both are sufficiently resourced to ensure effective monitoring as well as public and professional education/awareness raising.

4.6.2 The draft Bill requires additional safeguards to ensure that people with dementia are adequately protected. These include further guidance on assessment, robust mechanisms for people to challenge an assessment of incapacity and restrictions on the use of general authority to act. In addition, the Society recommends that a person who has been convicted of abuse should not be named as a deputy or a lasting power of attorney. Further debate is required on whether some professionals, such as a manager of a care home, should be appointed as deputies or LPAs because of the potential conflict of interest.

4.6.3 While it is right that the emphasis is placed on maximising decision-making, the Society would like to highlight the fact that people with most forms of dementia will deteriorate and eventually be unable to make any decisions for themselves. It is therefore essential that the proposals in the draft Bill recognise that most people with dementia will require ongoing protection and mechanisms for substitute decision-making. It will not be appropriate for carers to have to apply repeatedly for powers to act. As one carer explained:

"my husband who had multi-infarct dementia would have been quite incapable of decision-making for many years before his death."

4.6.4 The need for skilled assessment is vital to ensure that people are enabled to make as many of their own decisions as possible. However, skilled assessment is also essential to ensure that people with dementia are identified and that loss of capacity is recognised. Many carers reported that the problem was one of capacity being assumed when the person had dementia. Hospitals were frequently named as a setting in which staff seemed unaware of the needs of people with dementia.

4.6.5 Often, people with dementia do not have insight into their condition, or are unable to accept that something is wrong. One daughter wrote of her experiences:

"As a former nurse, my mother was extremely good at covering up her problems and was extremely plausible. Her doctor reacted with shocked amazement at our suggestion that my mother had dementia—'There's nothing wrong with your mother. I saw her only the other day and had a conversation with her. She's fine.' This was at a time when my mother was putting the electric kettle on the gas ring, entertaining phantom meetings of teachers in her front room, turning up at the hairdressers at 2am and living on a diet of biscuits having forgotten how to cook."

4.6.6 It is this group of people who are particularly at risk of neglect if proper assessment fails to occur. Health and social care professionals have often told distraught carers that there is nothing they can do if the individual refuses help. As one carer explained—"just because my mother knew the queen was called Elizabeth she was declared competent to make decisions and left in excremental squalor." The draft Bill must enable carers and professionals to act in the best interests of the individual.

4.6.7 Access to independent advocacy can also play a vital role in protecting the interests of people with dementia who do not have capacity. For example, one carer detailed a common scenario in which advocacy could help: "the greatest need is for the protection of those patients who have no close family to act as carer, or for those whose carer is also elderly and unable to act in a fully competent manner for a variety of reasons. My view in such cases is that an independent advocate should be appointed to ensure that the patient's interests are observed."

4.6.8 The draft Bill proposes that a person will not be able to force a person without capacity to comply with a proposed action unless it is essential to prevent a substantial risk of significant harm to the person concerned. The Alzheimer's Society believes that this is too wide a power and that the potential for abuse too high. For example, it might be interpreted by some that it is necessary to lock people in or restrain a person with dementia in order to prevent harm. The use of force should not be used unless immediate harm is imminent.

5. MIGHT LESSONS BE LEARNED FROM SIMILAR LEGISLATION ALREADY IMPLEMENTED IN SCOTLAND OR ELSEWHERE?

5.1 The Society has learnt a great deal from Alzheimer's Scotland—Action on Dementia and its experiences of helping to implement and monitor the Adults with Incapacity Act (2000). In particular, the Society encourages further discussion with colleagues in Scotland on:

- assessment of capacity
- resolution of conflict and the system for single shared assessment and review
- the best way to ensure that effective monitoring and safeguards are in place.

5.2 The widespread use of health proxies and advance directives across the United States means that there are sophisticated tools and support available to support people who wish to plan in advance for a time when they may no longer have capacity. The use of advance directives is common and useful checklists and guidance are widely available.

6. ARE THERE RELEVANT ISSUES NOT COVERED BY THE DRAFT BILL WHICH IT SHOULD HAVE ADDRESSED?

6.1 The Society has identified a number of important omissions in the draft Bill in paragraph 4. These include the lack of detail on how capacity will be assessed and by whom, as well as the need to include access to independent advocacy.

6.2 The draft Bill would be improved if its proposals were broadened to include advance statements, and not just advance directives. Advance statements help those appointed make decisions on what they know the person would have wanted and not just what they would have refused. For example, the use of advance statements would help avoid the situation in which a person is nominated to act as a health proxy/given lasting power of attorney for healthcare without actually having discussed with the donee what their wishes might have been.

6.3 The Society believes that advance statements are a valuable way in which people can document what they would like to happen if they lose capacity. The right to make an advance statement should be enshrined in law and understood to be valid documentation of an individual's wishes and preferences. The Society proposes that an advance statement is subject to the tests of reasonableness and practicality.

6.4 Interestingly, many carers who were partners/spouses felt that advance statements were not necessary because they knew what each other wanted:

“I was fortunate that after 52 years of a super marriage my late husband and I needed no tape recordings or diaries. We knew instinctively what the other half would wish.”

6.5 Not all of us are so fortunate, and many people with dementia will not have family or friends to care for them. Others recommended that “the best advice is to tell as many people in the family (and outside) of particular preferences in the hope that someone will remember them. If there is a written record you can re-read it.” Another suggested that “everyone should be encouraged to leave a personally written record. My friends and relatives do probably know my wishes—but that is not good enough.” One residential care provider shared their use of Department of Health consent forms to try and establish with family representatives what the person's previous views were, including the use of medication, group living, alternative therapies and the desire to be independent.

6.6 In addition, the Alzheimer's Society believes that the effective implementation of the draft Bill depends on significant investment in public and professional education/awareness raising.

6.7 Even under the current system of EPAs, which has been running for several years, huge confusion exists about the extent of the power conferred upon the attorney. Many mistakenly already believe that they have been given powers to make decisions on personal welfare and health matters. Indeed, following our consultation on the draft Bill one carer wrote:

“I am horrified. I thought as I had a power of attorney over my husband's affairs I had to be consulted regarding the giving of medication.”

6.8 It is not only members of the public that will need better information, but professionals as well. Carers acting under an EPA continue to report “a huge wall of ignorance, apathy and incompetence about the EPA. We might just as well have announced that we came from Mars.” But it is not only financial institutions and staff who will need to understand what a lasting power of attorney is, but a very broad range of professional groups. The awareness raising and training is therefore substantial and underpins the success of implementation of any new legislation.

6.9 The participation of adults without capacity in research raises many ethical issues. People in the early stages of dementia are still able to talk about their participation in current and future research. This means that they can be given the opportunity to both discuss the implications of participation in a research project and express their views with their carers and the professionals who care for them. People with dementia are capable of expressing their feelings and preferences well into the progression of the disease.

6.10 The Society supports the view that people who are unable to give legal consent to clinical trials should be given special protection. An attorney would only be able to consent to participation in research if they have been given specific powers to act as a “research proxy” through the creation of an LPA. Interestingly, research shows that proxies often have different views on participation in research than the people for whom they speak. This highlights the need for discussion and documentation of an individual’s views. Advance statements would also allow people with early stage dementia to express their broad wishes regarding research participation. Assent should always be obtained from the person with dementia. The Society also believes that the research proxy should be able to withdraw the person from the research at any point even if this contradicts the advance statement or any expressed preferences.

6.11 Non-therapeutic research, by definition, tends not to be in the individual’s best interests. Many people with dementia feel strongly that they wish to participate in research that may provide some good to other people and understand that they will derive no personal therapeutic benefit. Indeed, many people with dementia express such a sentiment to their carer and are willing to experience potential distress and discomfort in the hope that it will promote understanding. This is a complex area which is fraught with ethical problems. In particular, genetic research demands particular attention. The collection of a blood sample that could be used to analyse genetic data could be seen as non-therapeutic research. Research into the genetics of various forms of dementia may depend on people with a diagnosis donating their blood for research that is unlikely to have any direct benefit for them.

6.12 The attendant demands of protecting the best interests of the person with dementia and advancing knowledge through research may result in a conflict of interest between the person with dementia, their carer, and the researcher. While it is important that people with dementia have the same opportunities to participate in research as the rest of the population, they are a vulnerable group whose rights must be protected. Further work on the use of advance statements and research proxies would be welcome, given the different investments and interests involved.

7. SUMMARY

7.1 The words of people with dementia and their carers highlight the importance of this draft Bill:

“Introduce this Bill as soon as possible. Too many carers are struggling to cope with insufficient back up and no legal insights to care for their loved ones properly.”

“New legislation should be introduced as soon as possible so that people with dementia can benefit now and know that their views are important and taken into consideration. People without dementia have their say in their own treatment and so should we.”

August 2003

105. Memorandum from The Joint Medico-Legal Committee on Bioethics (MIB 885)

SUMMARY: ATTORNEY OR CONSULTEE—WHICH IS BEST?

1. We are of the view that the groundswell of opinion which seeks a greater role for patient advocacy or consultation is understandable and meritorious. The present difficulties being experienced by the National Health Service has resulted in an increase in the number of cases of dissatisfaction with the care of the elderly, vulnerable and chronically ill and a concomitant concern over what some see as a decline in standards in some hospitals.

2. The principal failure of understanding in the discussion of patient advocates and consultees is the failure to appreciate that they are fundamentally different in kind from the concept of attorney. An attorney “stands in the shoes” of the donor of the power of attorney and acts as if he were the donor.

3. Whilst that is a workable concept in the conduct of financial affairs, in medical matters the principle of autonomy requires that the patient himself or herself makes the decision to accept or refuse treatment since it will be his or her body that will be affected thereby. Lasting Attorneys, who need not be medically qualified, will nevertheless be making a decision about somebody else’s body and, importantly, can do so *without having any duty of care* and thus with almost complete impunity, even if they make a clinically negligent decision that harms the patient. That is a serious *lacuna*.

4. We support the idea of statutory consultees or patient advocates but not the potentially hazardous concept of Lasting Powers of Attorney (LPAs) or the related concept of legally binding Advance Decisions (ADs) in the sense set out in the draft Mental Incapacity Bill (MIB). Both an AD and an LPA may *require* a doctor to withhold treatment (even sustenance by tube) even if that forces the doctor to end the patient's life. A doctor could thus be prosecuted for *failing* to end a patient's life.

THE PROVISION OF BASIC CARE AND THE LEGAL BACKGROUND

5. The legal background must be considered when interpreting the various clauses of the MIB. In particular, the decisions in a few leading cases have tended to blur the distinction between medical treatment and the provision of "basic care" eg hygiene, pain relief and, particularly, food and fluids whether oral or by tube.

6. All previous consultation papers and draft bills have made at least a requirement for the provision of "basic care". That is apparently absent from the present draft. Thus it is not necessarily clear if such basic care—as a bare minimum—is obligatory. Most people will agree that all patients should be kept clean and, so far as possible, pain free. But the MIB makes no apparently obligatory provision for such "basic care".

7. Furthermore, the current position in case law as regards the provision of tube feeding is far from unambiguous. It appears that such may be regarded in some cases as "medical treatment" and thus could be withdrawn if a group of doctors felt it was not in a patient's best interests. If food and fluids, however delivered, are withdrawn from a patient who is not dying, the patient will *certainly* die from such withdrawal, usually by dehydrating to death.

8. The current state of case law, where relevant, is reviewed below⁴².

LASTING POWERS OF ATTORNEY (SS.8-13)

No Duty of Care owed by Lasting Attorneys

9. Provided an attorney acts within his given powers he cannot be sued, even if his decisions were clinically bad ones. Whereas doctors have a duty of care and can be sued for clinical negligence Lasting Attorneys cannot—they have no duty of care. The damage may cause financial loss to the donor. If the attorney is empowered to make medical decisions then the damage may be lasting or permanent physical damage or even death to the patient. It is important to realise that provided the attorney acts within his powers under the MIB he cannot be sued even if he makes clinically unsound decisions.

10. More importantly, the powers granted under an LPA can, if so framed, enable an attorney to *require* a doctor to withdraw or withhold treatment from the patient, because the attorney *stands in the shoes of the patient*—and the patient has an absolute right to refuse treatment when it is offered.

⁴² *The Bland Case*. In the leading case of *Airdale NHS Trust v Bland* [1999] AC 799, HL, the House of Lords were called upon to decide what should happen to a young man who had suffered severe brain damage after being crushed watching a football match and was rendered into the condition known as PVS, the Permanent or Persistent Vegetative State (which is not to say that he had become like a vegetable—a common misnomer). The court decided, among other things, that a patient in PVS could lawfully have his or her feeding tubes removed so that the patient then died of dehydration. The court said that, in the case of PVS patients, such feeding was medical "treatment" and could be withdrawn.

That distinction will be highly relevant in the case of Advance Decisions (AD) and Lasting Powers of Attorney (LPA) as will be seen because both can contain powers to refuse treatment. If treatment includes food and fluids delivered by tube then the donee of such powers or the AD itself could *require* medical staff to dehydrate a patient to death, a clear and unambiguous example not only of passive intentional killing (or euthanasia) but one that a doctor could be ordered to undertake on pain of very serious legal sanction.

Re M and Re H and Pretty: Bland has been declared compatible with the Human Rights Act in the cases of *Re H* and *Re M* [2001] 1 All ER 801, by the President of the Family Division, Dame Elizabeth Butler-Sloss on the rather unusual grounds that since the withdrawal of the food and fluids delivered by tube was a withdrawal of "treatment", such treatment can be withdrawn if a body of doctors expert in that field would have agreed it was appropriate. This seems to run counter to the principles set out in *R v Gibbins & Proctor* 13 Crim App Rep (1919) 134, (and other similar cases *R v Cox* (1992) 12 BMLR 38; *R v Bodkin-Adams* [1957] CLR 365 (CCC)) and, moreover, it is by no means clear that dehydrating PVS patients to death is a distress-free exercise so as to take the matter outside the range of "degrading and inhuman treatment" under Article 3 of the Convention. The decision may well be re-visited at a higher judicial level, particularly in the light of the decision in the case of *R (Pretty) v DPP (SSHD intervening)* [2001] 3 WLR 1598; [2002] 1 All ER 2; [2002] 1 FLR 268, in which the application of a person seeking help to commit suicide with legal impunity was refused.

The current law on Advance Decisions: It has been said by some that such are already binding in law. That is highly misleading and is an incomplete statement of the law as it now stands in the light of the leading case of *Re: AK* [2001] 1 FLR 129. It would be most helpful if the judgement of Mr Justice Hughes could be quoted in full as it offers very practical and explicit advice to doctors beyond which it is unnecessary to go. This is what the judge said at [2001] 1 FLR 134E-G:

"It is . . . clearly the law that the doctors are not entitled so to act if it is known that the patient, provided he was of sound mind and full capacity, has let it be known that he does not consent and that such treatment is against his wishes. To this extent an advance indication of the wishes of a patient of full capacity and sound mind are effective. Care will of course have to be taken to ensure that such anticipatory declarations of wishes still represent the wishes of the patient. Care must be taken to investigate how long ago the expression of wishes was made. Care must be taken to investigate with what knowledge the expression of wishes was made. All the circumstances in which the expression of wishes was given will of course have to be investigated. In the present case the expression of AK's decision are recent and made not on any hypothetical basis but in the fullest possible knowledge of impending reality."

Intentional termination of life—a new prospect under MIB

11. Given that the law recognises (see above) that in some circumstances even *food and fluids* by tube can be withdrawn (because they can be considered treatment in some circumstances) then a Lasting Attorney will have the power to *order* a doctor to withdraw sustenance from a patient. If sustenance is withdrawn then a patient *inevitably* dies. Thus it will be possible for Lasting Attorneys to have power effectively to *order* a doctor to bring about a patient's death.

12. Thus doctors could be required to terminate a patient's life intentionally. If the doctors does not follow the directive of the Lasting Attorney to withdraw the "treatment" (or even sustenance by tube) then that doctor may not only be liable in civil law but may be liable for the *criminal* offence of assault. If convicted he would be struck off the register.

13. Thus the MIB introduces a potentially odd situation whereby a doctor is *criminally* liable for assault if he does not bring about the termination of the patient's life deliberately and intentionally by withdrawing sustenance. This brings the law into immediate and serious disrepute by undermining the very law of homicide. To charge a doctor with assault for *not* terminating his patient's life is hardly reasonable, just or wise. Yet this could happen under the MIB.

14. One must also consider the effect upon the morale and ethical standards of the Health Service if doctors can be prosecuted for refusing to terminate a patient's life by withdrawing sustenance. The principle of "First Do No Harm" (*Primuni Non Nocere*) is compromised and the Hippocratic tradition of medicine undermined⁴³. If the doctor is now obliged to withdraw sustenance by tube from a patient on the direction of a Lasting Attorney then it can readily be seen that one of the most fundamental of medical ethical principles will have been breached permanently. Moreover, no doctor will be able to avoid the directive of the Lasting Attorney since the sanction for disobeying the LPA will be a very serious one ie criminal.

15. Members of the committee will be familiar with the case of Dr Harold Shipman. It can immediately be seen how much harder it would be to trace and apprehend doctors who take care to terminate their patient's lives when there is an LPA (or indeed AD). The activities of unscrupulous doctors will be given a plausible cover which might, in fact mask a deliberate intention to end life.

16. Further, one must consider the extent to which ending a patient's life by dehydration is a cruel method of terminating life. The body dries up, in effect. The eye sockets dry up, the skin becomes flakey and dry, the tongue dries up and turns black, and the brain sends distress signals all over the body: it is an unpleasant way to die and very unpleasant for relatives to observe. Relatives will ask why the patient cannot be given a lethal injection and, indeed, some have already said that such a death is cruel and that a lethal injection should indeed be administered. That, plainly, is a call for direct, involuntary, intentional killing and euthanasia.

Other potential abuses made possible

17. Consider further the situation where a Lasting Attorney is also a beneficiary under the patient's will and stands to gain financially by the patient's death. The scope for abuse is immediately obvious. And in many cases the attorney is *likely* to be a close relative who might also benefit from the will.

18. Lest this scenario be thought unlikely an example should assist.

19. In a Florida circuit court an order⁴⁴ was made withdrawing and withholding food and fluids from Marjorie E. Nighbert at the behest of her brother, Maynard Nighbert who held a durable (ie Lasting) power of Attorney. Miss Nighbert had suffered a stroke but it was said she had made indications of wishing to be fed. The court appointed a lawyer to investigate her capacity but it was concluded that she did not have capacity to withdraw the LPA and that her brother's decision to require the doctors to refuse food and fluids *must* be upheld.

20. Mrs Nighbert died not long thereafter from lack of food and fluids. Nurses said that she was still making signs requesting to be fed. It is thought that analgesic pain relief was administered but that is thought to be insufficient because dehydration acts upon the osmo-receptors in the brain which cause overall distress to the person and not just in the pain centres. Analgesics affect the pain centres not the osmo-receptors. Mrs Nighbert may well, therefore, have died in great distress.

21. This is but one example of the many ways in which an LPA can have the effect of undermining rather than enhancing a patient's autonomy.

22. Moreover the patient may not die but may, rather, suffer serious long-term damage instead.

23. Consider this example. A young man of 18 who is run over in a motor accident may have suffered a fractured femur but also been rendered unconscious with suspected brain damage. He may have an LPA which provides for the withdrawal of treatment in the event of mental incapacity. In that case the Lasting

⁴³ At present doctors are forbidden to participate in judicial executions because of the "No Harm" principle and because their vocation is to heal and alleviate pain. The most a doctor can do is testify that the condemned is certifiably dead.

⁴⁴ Case no. 95-4-PSA in the First Circuit Court of Okaloosa County (Probate Division), Circuit Judge Jere Tolton presiding.

Attorney may require the withdrawal of treatment on the grounds that the patient would not want to survive in a brain damaged state. The doctor would then be obliged to withhold treatment even though he could readily treat the fractured femur.

24. Now suppose that the patient after some months regains consciousness and, in fact, suffers little or no brain damage. despite the prognosis. The fractured femur will not heal itself and by the time some months have passed it may well be too late to heal it. The patient will thus be crippled for life—at the age of 18—and he will have no remedy against the Lasting Attorney (acting within the scope of the LPA), because the attorney has no duty of care and cannot be sued for clinical negligence. nor the doctor who will have had to follow the Lasting Attorneys demand to withhold treatment and thus is not liable.

25. Thus death may not ensue but, rather, lasting damage that could cripple a healthy person's life.

26. The same scenario could apply to an elderly person suffering from, eg stroke. A withholding of treatment may not necessarily result in the patient's death. They may simply deteriorate and live a miserable existence for a much longer period simply because, under the power of the LPA, the Lasting Attorney required the doctor to withhold treatment. This, indeed, appears to be what is happening in the *Schiavo* case in Florida, USA⁴⁵.

27. These are but a few of the potential hazards of introducing legally binding powers such as that of a Lasting Power of Attorney.

Consultee or Advocate is preferable to Power of Attorney

28. The desire for relatives, loved ones and friends to be consulted does *not* require anything so sweeping and far-reaching as a power of attorney. A legal requirement for them to be consulted as either statutory consultees or advocates is all that is required. Then if the doctor acts without consulting them he can expect to be open to a civil suit and/or a complaint to his professional body and the matter would be serious.

29. The unwelcome scenario of a doctor being *required* to act against his clinical judgement—or worse to terminate his patient's life—would, however, be avoided. Most patients simply wish to be sure that their appointed advocate or consultee is consulted so that they are kept fully in the picture by the medical staff and can see that the patient is being well cared for. That is what most people desire and a consultee or advocate can achieve that.

30. The establishment of a statutory power of attorney goes too far and is attended by very considerable risks not only to the patient but to the medical profession and to the general public as a whole. This is clear from ss.8, 10, 12 and 13 and the powers of the court set out in ss.21 and 22 do not obviate the problems outlined above since the court will be concerned to determine whether or not the LPA is valid, not whether the attorney's decision is clinically negligent. If the power is valid and not obtained by fraud or undue pressure, the court's interest lapses save in one circumstance.

31. That is outlined at s.21(3)(b), namely where the court is satisfied that the Lasting Attorney has behaved, is behaving or is proposing to behave in a manner incompatible with the patient's best interests. It can be seen below that there are considerable problems with the "best interests" criteria in MIB but the chief problem is that it is clear that, under the current state of the law (see above) and the wording of s.4 of MIB, it is not necessarily contrary to the patient's "best interests", as qualified by s.4, to suffer loss of life by the withdrawing or withholding of necessary treatment (or even sustenance by tube).

32. *Given the fact that many people, including doctors, will not be aware of the current state of the law, this aspect of the MID may well not be fully appreciated.* Once it is clear that "best interests" may not necessarily rule out the withdrawing or withholding of necessary treatment (or even sustenance by tube) from patients, then the dangers can be readily seen. Since the "best interests" criteria have been widened by s.4 to accommodate the concepts of LPA and AD it can be seen that the introduction of these concepts will permit the new "best interests" criteria to overrule *clinical* best interests so that a doctor can be *required* by the Lasting Attorney (and an AD) to do what his clinical judgement rejects—including even withdrawing and withholding sustenance by tube so that the patient then dies of dehydration. Thus it may not necessarily be against the patient's "best interests" to terminate his or her life by removing necessary treatment (or even sustenance by tube).

33. Moreover, s.21(3)(b) does not provide anything like the kind of protection that, at first blush, it appears to provide. Indeed, this paragraph is likely to serve to confuse rather than allay fears. It will give a deceptive impression of protection that is simply not there.

34. Likewise s.3(1), which stipulates that it will be an offence for a person to ill-treat or wilfully neglect the person over whom they have power of attorney or care. will not of itself prevent decisions to remove treatment or even sustenance by tube). The LPA (or AD) may require such and yet will still have to be followed. Thus. again, the wider and more subjective "best interests" criteria in s.4, which goes beyond

⁴⁵ Case no. 8:03-cv-1 860-T-26TTGW in the Tampa Division of the Middle District Court of Florida, following an order by District Judge Richard Lazzara on 30 August 2003.

clinical best interests and includes decisions under an LPA or an AD so that they are *by definition* within “best interests”, may permit withdrawing and withholding of necessary treatment (or even sustenance by tube) as being outside the patient’s “best interests”.

35. Thus, again, the scope of s.3 (1) is likely to cause untenable and misleading reassurance—a reassurance which is not justified.

36. Accordingly, the concept of Lasting Attorney would better be replaced with a concept of statutory consultee and/or advocate.

COURT-APPOINTED DEPUTIES (ss.14–20)

37. Of greater concern still is the power of the court simply to appoint a “Deputy” to make decisions to withdraw and withhold sustenance and treatment even though there is *no* LPA. Under s.17(1)(d) and (e) of MIB the court-appointed “Deputy” will have power to make “personal welfare” decisions including:

“giving or refusing consent to the carrying out or continuation of a treatment by a person providing health care for P”

38. Thus all the problems arising under LPAs are reproduced in the appointment of a “Deputy” *but* the “Deputy” will *not even* be appointed by the patient himself or herself but rather by a public body. Moreover, it is highly likely that such an appointee will be some official such as the chief Social Worker for the area concerned. Thus the chief Social Worker for the area is likely to be making decisions about the provision of treatment (or even sustenance by tube) to the patient and thus perhaps making a decision about whether that patient should continue to live or not, even though that social worker is not medically qualified and has no medical duty of care. That is clearly a matter for considerable concern.

ADVANCE DECISIONS (ss.23–25)

39. The concept of Advance Decisions is similar to the LPA save that instead of giving to an attorney the power to order withdrawing or withholding treatment, a legally binding decision or instrument is made by the patient themselves in advance of becoming incapacitated.

40. The same problems arise under these as with LPAs. The patient’s autonomy can actually be undermined by him or her being unable to revoke an AD due to lack of capacity whilst nevertheless wishing to be treated or receive sustenance.

41. For example, a patient may be “incapacitated” within the meaning of the MIB but still be able to hear or comprehend what is happening. A patient in certain types of condition can still hear and understand but not communicate their wishes to medical staff or others. The patient’s wishes may be overridden by their *own* AD which they are unable to revoke due to being unable to communicate. In such a situation the patient’s autonomy is exploded not enhanced if treatment is refused when the patient, in fact, desires it but cannot communicate that desire.

42. The obligations of the medical staff will be the same as with LPAs in the sense that any refusal by a doctor to withdraw and withhold treatment including, in some cases, sustenance by tube where the AD stipulates such withdrawal or withholding will put the medical staff at risk of civil and *criminal* sanction.

43. The same potential compromise of the law of homicide is thus risked by the legally binding AD.

44. Moreover, since there is nothing in the MIB which requires an AD to be in writing it seems that an oral AD may be sufficient. The scope for abuse in such a situation is correspondingly augmented to a considerable degree, since evidential difficulties are likely to arise along with competing assertions about the existence of an oral AD.

45. A person threatening suicide may be held to have made an AD if they state they do not want treatment even if the suicide threat is no more than a cry for help. Some suicides can appear very calm and rational but nevertheless still only intend no more than a cry for help. An AD may mean that they are not treated and simply die or suffer long-term harm.

46. Unlike the provisions for LPAs, there is not even an *attempt* to provide some sort of exclusion by the court on the basis that the AD is not in the patient’s “best interests”. It may simply be *assumed* that a patient’s best interests are served by his AD even if it requires the doctor to withdraw life-saving treatment, or even sustenance by tube, provided the purely technical formalities of the AD are met.

47. This demonstrates clearly that the “best interests” criteria in s.4 do not rule out the termination of life-saving treatment, the withdrawing or withholding of necessary treatment including probably even sustenance by tube, provided that is what the AD stipulates.

48. Once again, then, doctors will be in clear danger of being *required* to act contrary to their clinical judgment and even to be the immediate agent of the patient's likely death by withdrawing or withholding treatment and, where sustenance by tube is withdrawn or withheld, the patients' *certain* death⁴⁶.

49. Moreover, by s.25(3), a person who withholds or withdraws such treatment will not be liable even if there is *no* AD, provided he or she reasonably *believes* that there was one. That is a very wide "let out" clause and may result in withdrawal of treatment in disturbing situations, and even situations of unscrupulous conduct.

50. Thus, once again, the prospect of a criminal charge of assault arises for a failure to terminate the patient's life. This once again turns the law of homicide on its head and radically compromises a fundamental principle of universal medical ethics. It cannot be right for a patient's AD to *require* a doctor to terminate a patient's life by actively withholding sustenance however delivered. That is not to "let nature take its course" but rather it is to cause a patient to die of thirst. No doctor should be compelled to do such.

CAPACITY (ss.1–3)

51. It has been suggested that there is no settled law in relation to the definition of capacity. That is simply wrong as the President of the Family Division, Dame Elizabeth Butler-Sloss, has made clear in the case of *Re: B*⁴⁷. She said that:

"The general law on mental capacity is, in my judgment, clear and easily to be understood by lawyers . . . In a series of cases during the 1990s the House of Lords and the Court of Appeal restated the long-established principles which govern the law on mental capacity of adults and provided some guidelines in complex medical situations".

52. It is not necessary, therefore, to re-define capacity as MIB seeks to do.

53. Moreover, the definition in MIB has a number of flaws in the context of the remainder of the Bill. For instance, what constitutes "impairment of or a disturbance of the functioning of the mind or brain"?

54. It is very important to be clear because under the remainder of the provisions of MIB there may be decisions of life and death and any uncertainty about the limits of the definitions of incapacity may have potentially terminal consequences.

55. For the same reason it is potentially harmful to include within the definition a merely *temporary* impairment or disturbance. A patient may be in a position to regain capacity and may be merely unable to make a decision by reason merely of a temporary unconsciousness. If treatment were to be withdrawn by order of a Lasting Attorney that might pre-empt a decision that could be made by the patient upon his or her returning to capacity. But the patient may be dead before then. That is plainly a very serious *lacuna* in the definition of capacity.

56. For the present approach of case law to capacity, see *inter alia*, *Re: C* and *Re: T*⁴⁸.

57. A case law approach is to be preferred rather than the blanket statutory approach to capacity that is suggested in MIB.

BEST INTERESTS (s.4)

58. The attempt by previous draft bills, Green papers and consultation papers to redraw "best interests" criteria in a non-clinical manner has been a continuing source of difficulty and controversy.

59. There is an intrinsic contradiction contained within such a definition. Medical practitioners are primarily concerned with determining what is in a patient's *clinical* best interests. They are hardly in a position to determine what is in a patient's non-clinical best interests since that is a matter for the patient's own autonomy. The patient's autonomy to determine matters of a non-clinical nature cannot logically be alienated to a third party, whether by statute or by LPA.

60. Clinical best interests do not necessarily coincide with patient wishes. Indeed, a patient may want what is not clinically indicated or refuse what is medically necessary. The question of patient autonomy in decision-making must not be confused with medical opinions as to the clinical best interests of the patient which are a matter of professional judgement. A doctor is not empowered to advise upon non-clinical best interests and it cannot be right to *require* him or her so to do.

⁴⁶ The concept of an AD appears to have been first put before Parliament in 1993 in the Medical Treatment (Advance Directives) Bill [HL Bill 73, 1993], by a peer on behalf of the Voluntary Euthanasia Society. This is perhaps unsurprising because it is a legal device for *compelling* doctors to act in a manner that will terminate the life of a patient intentionally, thus forcing the doctor to act contrary to the fundamental principle of medical ethics to do no harm (*Primum Non Nocere*) which has always been one of the primary objections to euthanasia—voluntary or otherwise. It is not voluntary for the doctor faced with a legally binding AD. Thus legally binding ADs could, for the first time, require a doctor to terminate a life and the doctors failure so to do may amount to a criminal offence of assault. This will be so if "treatment" is to include sustenance by tube. Removal of feeding tubes from a patient who is not dying will ensure that the patient dies *directly* as a result of that removal of tubes. And that removal will have to be carried out by a doctor or a nurse.

⁴⁷ [2002] 1 FLR 1090 at 1095.

⁴⁸ [1994] 1 WLR 290, *per* Thorpe J; [1993] Fain 95.

61. S.4 of MIB includes a raft of criteria that are not objective and clinical but are vague and subjective. It makes no reference to the criteria in *F v West Berkshire HA (Re: F)*⁴⁹ which sets out an objective framework for clinical best interests which is easily understood by doctors, the courts and the public.

62. In matters of life and death it is most unwise to obfuscate the criteria by which doctors must act.

63. In addition there is a substantial “let out” clause in s.4(4) in that a carer need only have a “reasonable belief” that they act in a patient’s best interests. Since the outcome might be the death of the patient that is simply not sufficient and removes existing protection that incapacitated patients have in law.

THE GENERAL AUTHORITY (SS.6–7)

64. There is simply no requirement for a “general authority” since such already exists at common law as is clear from, *inter alia*, the case of *Re: F*⁵⁰.

65. Moreover, s.7(1)(b) mentions “risk of significant harm to P” but does not make it clear whether or not that means death in all circumstances. That is important since it is sometimes considered that death is not “significant harm” for certain types of patients—a subjective concept which has obvious potential for undermining a patient’s autonomy and a doctor’s ethical obligations.

THE HUMAN RIGHTS ACT 1998 AND THE EUROPEAN CONVENTION ON HUMAN RIGHTS

66. In the light of the above, it is our view that the MIB may not be fully compliant with the Convention, particularly Articles 2 and 3. The recent decision in the Diane Pretty case reinforces our view⁵¹.

67. In particular we consider that:

- a. MIB appears to be incompatible with Article 2 of the Convention because it appears to fall foul of the state’s obligation to provide protection of the right to life which right is a positive obligation on the part of Member states.
- b. MIB does not provide the necessary framework within the context of Article 6 to protect the right to a fair hearing in protection of the individual citizen’s right to life under Article 2 and right to be free from inhuman and degrading treatment under Article 3. Dehydration to death must surely amount to inhuman treatment if not more.

CONCLUSION

68. We believe that the concepts of LPA and AD contain flaws of a fundamental nature that not only fail to answer and address the problem of autonomy and protection but, indeed, undermine both.

69. We believe that the better course for the assurance of proper consultation of relatives, loved ones and friends in the care and management of patients with mental incapacity is a system of statutory consultees and/or patient advocates.

70. Such a system would meet the desires of most patients and would, we believe, obviate most of the situations that have been adumbrated by representative organisations seeking to protect and enhance the autonomy of patients and the protection of the vulnerable incapacitated patient.

September 2003

106. Memorandum from The Society for the Protection of Unborn Children (SPUC) (MIB 890)

EXECUTIVE SUMMARY

Capacity—the Bill is not needed to define capacity, since good case law provides this. Best Interests—The Bill departs radically from the existing, well-understood, long-established criteria. The proposed criteria are incomplete and will be inflexible if written into statute. The “wishes and feelings” test is prejudicial to those who lack self-esteem. Patient autonomy is an important value, but is not a patients only interest.

Advance Decisions and Lasting Powers of Attorney (LPA)—Doctors already have a common law duty to treat incompetent patients. This arises from the principle of necessity, directed to the patient’s best interests. For the incompetent patient, medical decision-making should be the prerogative of medically

⁴⁹ [1990] 2 AC 1.

⁵⁰ *Ibid.*

⁵¹ *R (Pretty) v DPP et al* [2001] 3 WLR 1598.

qualified personnel. The advance decision mechanism in the bill lacks the most rudimentary safeguards—such as the need for an impartial witness, and for the patient to be informed about the treatments being refused.

The safeguards against advance decisions being misapplied are woefully inadequate.

The advance decision and lasting power of attorney provisions, would have the effect of going much further than the Bland judgement on a statute basis—it would undermining the provision of care for incapacitated people very widely.

Those trying to save the lives of attempted suicides could be penalised by the Bill.

Doctors should not be forced to complicity in suicide or euthanasia—assisting suicide and euthanasia are unethical and at present remain illegal. These are important provisions for the protection of vulnerable members of society.

Patients should be discouraged from regarding their lives as worthless.

Advance decisions could be made under duress, or falsely reported. Lasting powers of attorney are susceptible to equally serious or worse abuses.

Donees of LPAs would have neither appropriate medical expertise nor legal answerability to make healthcare decisions. They might also have an interest in the patient's death. LPAs would be particularly potent (and hence risky) in the context of the distorted best-interests criteria in the Bill.

Contrary to the Joint Committee on Human Rights, Richard Gordon, QC, points to serious risks of infringements of convention rights due to limitations on access to the Court of Protection.

The Bill will lead to some patients being seriously harmed by neglect who will not die in short order, but rather become chronically incapacitated and increasingly ill and bed-ridden, while the law forbids doctors to treat them.

The government's claim to be opposed to euthanasia is belied by its promotion of euthanasia by omission in this bill.

It is imperative that the Government should ensure that any legislation it proposes does not allow omissions of treatment or care which are undertaken with the intention that death results.

1. The Society for the Protection of Unborn Children (SPUC) is a lobbying and educational membership organisation, founded in London in 1967 to defend human life from conception to natural death. It has members of all faiths and none, and the Society is not allied to any particular denomination or faith. SPUC has been invited by parliamentary committees to submit evidence on a range of topics. SPUC gave evidence to the House of Lords Select Committee on Medical Ethics in 1993, which considered a number of issues relevant to the current draft Mental Incapacity Bill (henceforth "the draft MIB").

2. SPUC's particular areas of concern regarding the MIB are:

- incapacity,
- best interests,
- advance decisions to refuse treatment,
- lasting powers of attorney, and
- the court of protection.

We comment further on the issues of:

- non-treatment and neglect,
- euthanasia by denial of sustenance,
- the government's stance on euthanasia,
- misconceptions regarding the Bill, and
- the government's legislative plans.

Incapacity

3. The definition of incapacity in section 1(2) as including temporary incapacity could apply to someone who is intoxicated or affected by the accidental or deliberate consumption of "recreational" or medicinal drugs. In considering the effects of the Bill, consideration must be given to the impact of the best interests criteria, advance decisions and lasting powers of attorney in such cases.

4. Temporary incapacity following an apparent suicide attempt should not be regarded as justifying non-treatment on the basis of a suicide note or any other statement which may be construed as an advance decision to refuse treatment.

5. SPUC is also concerned that donees of lasting powers of attorney (LPAs), in determining capacity in the donor, are not subject to sufficient checks and balances, and the bill contains a serious threat to the lives of patients signing LPAs (see section below on Court of Protection).

6. Since a common-law test for determining capacity already exists (paragraph 97–111, “Misconceptions regarding the Bill”), a statutory definition and test for capacity is unnecessary.

Best interests

7. At present, there is no statutory definition of a patient’s “best interests,” which may be surprising as this is such a critical notion in many legal decisions relating to how individuals should be cared for. Despite the lack of statutory guidance, it is a notion refined by decades of application in medical and social fields, and by a number of important legal judgments. “Best interests” in medical terms are generally understood, as is reflected in case law,⁵² to include such basic factors as preserving life, maintaining or restoring health and minimising suffering. These factors command extremely wide support in the community and are uncontroversial and (relatively) easy to apply for doctors. They commend themselves in principle as the basis of an ethical approach. Any other of the criteria sometimes suggested for the determination of best interests should be advisory, not decisive.

8. In *re F*⁵³, the court held that at common law a doctor can lawfully operate on or give other treatment to adult patients who are incapable of consenting to his doing so, provided that the operation or treatment is in the best interests of such patients. The operation or treatment will be in their best interests *only* if it is carried out in order either to save their lives or to ensure improvement or prevent deterioration in their physical or mental health. [our emphasis]

9. Furthermore, to legislate on the meaning of “best interests” is to risk codifying a system that departs radically from the traditional approach, to the detriment of patients. Leading public lawyer Richard Gordon QC has stated: “The obvious scope for treating vulnerable persons contrary to their best interests in MIB and in a way which deprives them of life is considerable.”⁵⁴

10. Resolving controversies over the application of “best interests” would not be achieved simply by legislation, which would itself be subject to interpretation by the courts. However, to incorporate a novel view of “best interests” into statute law may leave the courts with less freedom to interpret the law to the benefit of vulnerable people.

11. Another danger is that although the draft MIB relates specifically to mentally incapacitated adults, once legislation is enacted which incorporates “best interests” criteria, these criteria may be used by the courts as terms of reference for determining “best interests” in other situations, entrenching further this inadequate approach.

12. At present there is a “presumption in favour of life” where the patient is not competent to consent to treatment. The approach taken in the draft MIB would undermine that principle in law and medical practice.

13. The draft MIB suggests that “best interests” are determined in the light of the ascertainable “wishes and feelings” of the incapacitated person. Relying on “wishes and feelings” suggests that a person’s life is not worthwhile, and is not to be treated as worthwhile by others, unless the individual recognises it as such. For instance, those who are suicidal “feel” that they would be better off dead and “wish” to die. For them, death could be regarded as being in their “best interests” if this definition were used, and they could well be denied life-saving interventions.

14. The draft MIB places the notions “wishes” and “feelings” together. Often they will coincide, but sometimes they will contradict. A person may feel angry or aggrieved at having to endure medical procedures, but still indicate a wish to undergo them. In the case of an incompetent patient, whose presumed wishes and feelings are in tension, how will a decision be made?

15. We have reservations about certain applications of the *Bolam*⁵⁵ test, in which a doctor is considered not to be acting negligently if he acts “in accordance with a responsible and competent body of relevant professional opinion.” Our reservations are concerned largely with the use of that principle to support judgments (eg *Bland*⁵⁶) which are objectionable when tested against more fundamental ethical principles. However, the *Bolam* test is much preferable to a situation in which liability for “negligence” could hinge not on a clinical test but on failure to canvass the “wishes and feelings” of relevant parties.

16. Doctors are required to consider each individual patient’s best interests. However, it is a mistake to assume that because each individual case may require a different course of treatment in pursuit of the best interests, that best interests coincide with the particular patient’s wishes prior to becoming incapacitated. “Best interests” do not always coincide with the choices a patient makes, or might have made before

⁵² *F v West Berkshire HA; Re: F (Mental Patient: Sterilisation)* [1990] 2 AC 1.

⁵³ *Ibid.* p 2

⁵⁴ Opinion on the draft Mental Incapacity Bill at 74.

⁵⁵ *Bolam v Friern Hospital Management Committee* (1957) 1 BMLR 1, [1957] 1 WLR 582.

⁵⁶ *Airedale NHS Trust v Bland* [1993] AC 789 (HL).

becoming incapacitated. Choosing not to observe the incompetent person's wishes does not necessarily imply disrespect for the individual or contravene his or her rights. Doctors often need to make treatment decisions against the competent patient's wishes, but in their best interests, eg when a patient asks for a prescription, the doctor will consider whether or not it will benefit the patient.

17. In legal terms, competent patients have an absolute right to refuse treatment. However, this expression of a juridical ideal must be viewed in the light of everyday practice. The exercise of that right is not always straightforward, and the offer and acceptance (or refusal) of treatment may be bound up with other factors. A TB patient for example, may freely give an assurance that he will complete the course of medication his doctor offers. Is he free, on a whim, to exercise his "absolute legal right" to stop the treatment halfway through? Is it right for doctors to try to attach any "conditions" to an offer of treatment? Some treatments may be ineffective or risky if certain conditions are not observed: "Don't drive or operate machinery after taking this drug", etc.

18. Autonomy, while being important, is not the only interest a patient has. The exercise of autonomy depends on the more basic interests of life and health. These interests become especially important if a person becomes incapacitated, a circumstance in which the patient can no longer exercise autonomy. Regardless of any decrease in autonomy, an incapacitated person still has intrinsic dignity and a right to live simply by virtue of being human.⁵⁷

19. An individual's best interests and his wishes do not always coincide. As Richard Gordon QC has noted with reference to powers of attorney:

"... the statutory criteria [for best interests proposed in the MIB] are an attempt to put the donor in the position of a person with capacity. But there is no true analogue because a person with capacity may often act autonomously but contrary to his or her best interests. This attempt at substituted capacity reflects an internal contradiction in the logic of best interests."⁵⁸

20. Moreover, a patient's autonomy may be undermined if a decision is made at a time when the patient is unable to communicate his dissent from it.

21. SPUC submits that the proposed legislation for determining "best interests" criteria is undesirable since it depart radically from existing well-understood, uncontroversial principles and also risks imposing a narrow and dangerous definition.

Advance and proxy-decision making in general

22. Lord Brandon of Oakbrook said in *Re: F*⁵⁹:

"In many cases . . . it will not only be lawful for doctors, on the ground of necessity, to operate on or give other medical treatment to adult patients disabled from giving their consent: it will also be their common law duty to do so."

Legally-binding advance decisions and powers of attorney may prevent doctors from fulfilling their existing common-law duty.

23. Lord Brandon also said in *Re: F*⁶⁰:

"If doctors were to be required, in deciding whether an operation or other treatment was in the best interests of adults incompetent to give consent, to apply some test more stringent than the Bolam test, the result would be that such adults would, in some circumstances at least, be deprived of the benefit of medical treatment which adults competent to give consent would enjoy. In my opinion it would be wrong for the law, in its concern to protect such adults, to produce such a result."

The MIB, by making doctors obey legally-binding advance decisions and powers of attorney, would create the kind of more stringent test that Lord Brandon warned against, and thereby deprive incompetent patients of the benefit of medical treatment which adults competent to give consent would enjoy. It is important here to note the ruling by Butler-Sloss LJ in *NHS Trust v S, DG & SG*⁶¹ that depriving an incompetent patient of the benefit of medical treatment which a competent adult would enjoy is contrary to English and European law.

⁵⁷ The Universal Declaration of Human Rights 1948 forbids discrimination on the basis of "personhood". It declares that "everyone has the right to recognition everywhere as a person before the law (Article 6), and that "everyone is entitled to all the rights and freedoms set forth in this declaration, without distinction of any kind" (Article 2).

⁵⁸ *Ibid*, p 3, at paragraph 59 of opinion.

⁵⁹ *Ibid*, p 2.

⁶⁰ *Ibid*, p 2.

⁶¹ [2003] EWHC 365 (Fam).

⁶² *Ibid*, p 2.

24. SPUC submits that while due consideration must be given to patients' and relatives' concerns, the present situation in which medical decision-making for incompetent adults is the responsibility of medical professionals is much preferable to the poorly-designed provisions of the draft MIB. Lord Goff said in *Re: F*⁶²:

"Take the example of an elderly person who suffers a stroke which renders him incapable of speech or movement. It is by virtue of this principle that the doctor who treats him, the nurse who cares for him, even the relative or friend or neighbour who comes in to look after him will commit no wrong when he or she touches his body."

Lord Goff also quoted Lord Donaldson MR:

"I see nothing incongruous in doctors and others who have a caring responsibility being required, when acting in relation to an adult who is incompetent, to exercise a right of choice in exactly the same way as would the court or reasonable parents in relation to a child, making due allowance, of course, for the fact that the patient is not a child, and I am satisfied that that is what the law does in fact require."

The common-law does not restrict this principle of necessity to emergencies: Lord Goff also said in *Re: F*⁶³ that:

"the historical origins of the principle of necessity do not point to emergency as such as providing the criterion of lawful intervention without consent."

25. According to Butler-Sloss LJ⁶⁴, doctors have two distinct legal duties to their incapacitated patients: first, to act at all times in accordance with a responsible body of medical opinion secondly, to act in the best interests of the mentally incapacitated adult. The provision for legally-binding advance decisions and proxy decision-making under the MIB would undermine the first of these duties, and make the second meaningless. Advance decisions and lasting powers of attorney would over-ride medical opinion, and by effectively excluding medical criteria from best interests, the notion of a responsible body of medical opinion is further obscured.

26. Legally binding advance and proxy decision-making might also work against patient autonomy because the inflexibility of their legally-binding nature does not take into account that patients often change their mind, as Butler-Sloss LJ said in *Re: MB*⁶⁵:

"... A feature of some of the cases to which we have referred has been the favorable reaction of the patient who refused treatment to the subsequent medical intervention and the successful outcome."

27. Legally-binding advance decisions and powers of attorney would diminish the autonomy of doctors, forcing them to act in what has hitherto been regarded as a medically negligent way.

Advance decisions

28. In *Making Decisions* (introduction, 20) the Government said:

"The courts . . . have determined that certain forms of advance statement already have full effect at common law . . . Given the division of opinion which exists on this complex subject and given the flexibility inherent in developing case law, the Government believes that it would not be appropriate to legislate at the present time, and thus fix the statutory position once and for all. The Government is satisfied that the guidance contained in case law, together with the Code of Practice *Advance Statements about Medical Treatment* published by the British Medical Association, provides sufficient clarity and flexibility to enable the validity and applicability of advance statements to be decided on a case-by-case basis. However, the Government intends to continue to keep the subject under consideration in the light of future medical and legal developments."

29. One of the "legal developments" since *Making Decisions* was issued was the ruling by Mr Justice Hughes in *Re: AK*⁶⁶, "case law" which helps even further to "provide sufficient clarity and flexibility to enable the validity and applicability of advance statements to be decided on a case by case basis":

"It is . . . clearly the law that the doctors are not entitled so to act if it is known that the patient, provided he was of sound mind and full capacity, has let it be known that he does not consent and that such treatment is against his wishes. To this extent an advance indication of the wishes of a patient of full capacity and sound mind are effective. Care will of course have to be taken to ensure that such anticipatory declarations of wishes still represent the wishes of the patient. Care must be taken to investigate how long ago the expression of wishes was made. Care must be taken to investigate with what knowledge the expression of wishes was made. All the circumstances in

⁶² *Ibid*, p 2.

⁶³ *Ibid*, p 2.

⁶⁴ SL (by her litigation friend, the Official Solicitor) v. SL (her mother) [2000] EWCA Civ 162.

⁶⁵ *Re: MB* [1997] EWCA Civ 1361.

⁶⁶ [2001] 1 FLR 134 E-G.

which the expression of wishes was given will of course have to be investigated. In the present case the expression of AK's decision are recent and made not on any hypothetical basis but in the fullest possible knowledge of impending reality."

30. Even by the Government's own standards, therefore, it is unnecessary to legislate for advance decisions.

31. Yet not only will the draft MIB contradict *Making Decisions* and "fix the statutory position once and for all", it will go radically beyond the ruling in *Re: AK*, as any validly made out "advance decision" would now become a binding legal instrument regardless of how old it is, or how ill-informed or uninformed about the condition or the treatment the patient might be.

32. The exclusions in section 24(4) of the MIB provide no mechanism for testing whether "circumstances exist which were not anticipated by P at the time of the advance decision and which would have affected his decision had he anticipated them."

33. It could be argued that this is a widely drawn exclusion. However, judging by existing pro-forma advance directives, little detail is likely to be given of the circumstances in which they are intended to come into effect. They are presumably drafted in this way to ensure applicability in the widest range of circumstances. Enthusiasts for advance directives may decide that they wish to maintain this approach, since clause 24(4)b will invalidate the advance decision if any explicitly specified circumstances are absent.

34. Secondly, some way is required to determine which of the circumstances now obtaining that were not specified would have affected the patient's decision if he had been able to predict them. This is a huge speculative question. What kind of evidence would be required? Who should be consulted or have a right to be heard? How would disputes be resolved?

35. Consider a person making an advance decision saying: "If I become incapacitated as a result of brain injury, degenerative illness or dementia, I wish only to have basic care, and no invasive treatment, surgical intervention, resuscitation or other intensive treatment. This is to apply equally to life sustaining treatment." What if this person loses capacity through dementia, but then suffers a bowel obstruction, which surgery could rectify but may otherwise be fatal? How could it be decided if this is a circumstance that the patient anticipated or not? And if it was decided that he had not anticipated this situation, how would one know whether it would have affected his decision?

36. The new treatments which the patient could not have foreseen being developed since making his advance decision will not automatically be permitted for the patient, but the question would have to be somehow addressed: how would this have affected his decision?

37. Since the *Bland*⁶⁷ judgement, food and fluids delivered by tube have been considered "medical treatment" and therefore can be withdrawn or withheld by doctors. The draft MIB would give statutory force to advance decisions, including decisions to refuse "treatment" including food and fluids.

38. Advance decisions should not be used to force healthcare professionals into complicity with a patient's intent to bring about his own death.

39. Any system using advance decisions must prevent them being used to bring about the deaths of patients. In the *Bland*⁶⁸ case, Lord Mustill noted that:

"It is a striking fact that in 20 of the 39 American states which have legislated in favour of 'living wills', the legislation specifically excludes termination of life by the withdrawal of nourishment and hydration."

40. Among the many problems of advance decisions are that: it is impossible to predict in advance what one will want in a situation not previously experienced; ones wishes and feelings will almost necessarily change following incapacity; ones ability to form wishes and feelings are likely to be impaired by incapacity; new treatments may become available which the person signing the advance decisions could not have foreseen.

41. Under the draft MIB, revocation of the advance decision requires "capacity" otherwise it is valid and binding. The Bill states that the advance decision is not valid if the patient does "anything else clearly inconsistent with the advance decision remaining his fixed decision." This sounds helpful, but in practice it would provide little or no safeguard because the inconsistent act will only count if the person has "capacity"—and who will give evidence to the "inconsistent act"? Medical staff may be placed under such great pressure to free hospital beds that they may feel unwilling or unable to give the necessary evidence.

42. The House of Lords Select Committee on Medical Ethics, which reported in 1994, opposed giving advance decisions greater legal force, saying this would risk

"depriving patients of the benefit of the doctor's professional expertise and of new treatment and procedures which may have become available since the Advance Directive was signed."⁶⁹

⁶⁷ *Ibid*, p 3.

⁶⁸ *Ibid*, p 3.

⁶⁹ Report of the Select Committee on Medical Ethics. Printed 31 January 1994 Paragraphs 263 and 264.

43. Unlike LPAs, advance decisions will not have to be registered, allowing for them to be made orally (ie the person only has to say s/he wants to refuse treatment in particular circumstances—it need not be written down.) Thus all that would be needed for such a statement to be binding would be someone to say “I heard Mrs. Smith say she didn’t want to be treated if she was in this condition”. In such circumstances it would then be illegal for the doctor to give the patient treatment—presumably including tube-delivered food and fluids—if the patient had specified refusal of life-sustaining treatment.

44. The draft MIB creates punishments for “concealing or destroying” an advance refusal of medical treatment. Now that tube-delivered food and fluids are regarded as medical treatment, this means that a person could be punished for trying to prevent a patient being starved and dehydrated to death, and doctors could be punished for saving a life by refusing to withdraw or withhold food and fluids from a vulnerable person.

45. Also, such a provision could criminalise parents, for example, who destroy or conceal their son’s suicide note, fearing (with good reason) that if doctors become aware of it he will not be treated. This scenario illustrates the fact that, ethically, it is defensible—or even imperative—to conceal an expression of someone’s wishes in order to prevent the accomplishment of his intention to bring about his own death. Ordinarily, it would be wrong to withhold from those responsible for a person’s health care an expression of his or her wishes which needs to be taken into account in decision-making. Ethical problems arise, however, when an advance refusal is liable to be treated as binding.

46. The best way to obviate the difficulties in creating the specific offence envisaged is to refrain from legislation for advance refusals.

47. While an advance refusal is likely to protect the doctor against an action for medical negligence, the patient would thereby be deprived of the protection afforded by the possibility of legal action.

48. The advance directive drawn up by the Voluntary Euthanasia Society reads: “I wish it to be understood that I fear degeneration and indignity far more than I fear death. I ask my medical attendants to bear this in mind when considering what my intentions would be in any uncertain situation.”⁷⁰

49. Under section 24(5) of the MIB, a statement such as this is likely to be regarded “an indication to the contrary” over-riding the presumption in favour of life. It is equally likely that a statement so worded, especially when made by a member of the Voluntary Euthanasia Society, is based on a belief that life loses its value under certain conditions and that its end is not merely tolerable but may become the object of one’s intentions.

50. In such circumstances an advance directive, if binding once its author becomes incapacitated, would thus be an instrument of its author’s intention to cause his own death, and therefore morally unacceptable.

51. Doctors who refuse on clinical or other ethical grounds to implement an advance refusal face litigation and possibly criminal conviction. Even in situations where there is no obligation to provide therapeutic measures (for example, when they are ineffective) there remains a duty of care towards the patient. It would be unreasonable, and immoral, to force healthcare professionals to relinquish this responsibility because of their conscientious objection to implementing clinically inappropriate or unethical advance refusals.

52. A further practical problem: how would a conflict between two undated written advance refusals be resolved, in the absence of evidence as to which was the more recent? (Indeed, how would a doctor act in the face of conflicting statements in the same advance directive?)

53. SPUC submits that it is unnecessary to legislate for advance decisions; and the MIB is prejudicial to the welfare of patients who have made advance refusals, since it would protect bad clinical practice and criminalise good clinical, ethical practice.

Lasting powers of attorney

54. The House of Lords Select Committee on Medical Ethics concluded that a system of proxy decision-making:

“is vulnerable to the same problems as advance directives, and indeed to a greater degree.”⁷¹

55. It is important to distinguish between two kinds of statement by proxy. A proxy may (a) be communicating preferences expressed by the patient himself before he became incapacitated; or (b) be making his own judgment as to the likely preferences of the patient.

56. As a matter of good practice, a doctor should take into account any statement that he reasonably believes to belong to category (a). However, doctors must be much more cautious about proxies in category (b).

⁷⁰ Quoted in *Law Com 231* (Report), paragraph 5.9.

⁷¹ *Report of the Select Committee on Medical Ethics* (1994), Vol 1, paragraph 268.

57. Regardless of the understanding of the proxy's role, such a proxy decision-maker would not need to be medically or legally qualified; would not be not legally accountable for the consequences of whatever advice or instructions that he may give to medical staff; and may benefit in some way, especially financially, from the patient's death.

58. Such a proxy decision-maker might order the patient to be deprived of care or treatment with the intention of bringing about the patient's death, on the grounds that the incapacitated patient "wouldn't want to live like this".

59. The concept of autonomy would become corrupted to a concept of substituted judgment and euthanasia would become an option even if the patient had not asked for it.

60. Only the senior clinician in charge can be expected to be suitably qualified to make decisive judgements as to the appropriate medical care and treatment for the patient, and only such senior clinician can be expected to be accountable for such judgements.

61. Lord Brandon of Oakbrook said in *Re: F*⁷²:

"In my opinion, the principle is that, when persons lack the capacity, for whatever reason, to take decisions about the performance of operations on them, or the giving of other medical treatment to them, it is necessary that some other person or persons, *with the appropriate qualifications*, should take such decisions for them." [our italics]

LPAs will not in general be qualified to make medical decisions.

62. This does not mean that the patient may be subjected to whatever treatments and decisions the doctors care to make. The doctor must seek the patient's restoration of health, prevention of impairment and alleviation from suffering, whilst always protecting the patient's life.

63. Proxies are by their nature, more prone to introduce extraneous considerations—their own feelings and interests, or those of other people, which are neither relevant to the autonomy principle nor to the doctor's duty to serve his patient's best interests. As the court held in *Wilsher*⁷³, the duty of care ought to be tailored to the acts rather than the individual themselves. Doctors experienced in the medical conditions that patients experience are in a better position than relatives or friends to decide which medical acts best fulfill the duty of care towards their patients.

64. We also note that a non-medical proxy could not be liable at all for medical negligence: a further lack of protection for patients.

65. Doctors may properly act in accordance with a proxy's statement if it is not against their clinical judgment to do so, and if they reasonably believe that the proxy is expressing the patient's own wishes. Doctors are already free to take this approach, and there is no advantage in new legislation (whereas the dangers, as we note, are considerable).

66. SPUC submits that LPAs applying to healthcare decisions require much more stringent safeguards than the draft MIB provides and pose an extremely serious threat to patients as the draft stands. An attorney's refusal of treatment should not be legally binding and there should be no lessening at all of the current liability, civil or criminal, that applies to doctors.

The Court of Protection

67. Under the MIB, the Court of Protection would have its functions redrawn to underwrite decisions to withdraw food and fluids from vulnerable people, and thus to cause their deaths. There may be insuperable problems for any judge opposed to medical killing sitting on the Court of Protection, because they may well have to take part in its function of supporting decisions that mentally incapacitated people be starved and dehydrated to death.

68. We foresee that the courts may resolve any conflict between the draft Mental Incapacity Bill and the Suicide Act 1961 by instituting the practice that healthcare professionals are exempt from penalties for complicity in suicide, provided that they act in accordance with the new legislation.

⁷² *Ibid*, p 2.

⁷³ *Wilsher v Essex AHA* [1986] All ER 801 (CA).

69. Richard Gordon QC has concluded that:

“... the legal threshold at which a donee [of a lasting power of attorney] is empowered to make life or death decisions on behalf of the donor is ... not subject to effective control by the Court prior to the action being taken.” (opinion at 59).

“Article 6(1) ECHR provides materially that: In the determination of his civil rights and obligations or of any criminal charge against him, everyone is entitled to a fair and public hearing within a reasonable time by an independent and impartial tribunal established by law. “It is also well established that even a temporary impediment on access may violate this right.” (opinion at 49)

“... there is no mechanism for the Court to become involved at all. There is no compulsion on a donee [of a lasting power of attorney] to bring the matter before the Court at all. This is, to my mind, a serious omission in Article 6 protection in this area of the law given the substantial and effective protection that are considered to be fundamental to ECHR protection.” (opinion at 63)

“It is also, to say the least, a temporary impediment to access (and therefore, also a breach of Article 6) for obviously interested parties (such as those exercising general authority under clause 6) to require the leave of the Court under clause 40(2) and for there to be a general prohibition against applications without leave under clause 40. *A fortiori* given the fact that there is no statutory mechanism for the involvement of the Court at all.” (opinion at 63).

“The right of access to a Court under clause 40 is, in my view, inadequate to comply with the need for immediate access to a Court, without impediment, to safeguard the interests of incapacitated persons in an area of considerable moral and ethical controversy which may, in many instances, be at variance with objective clinical judgement.” (opinion at 61)

70. SPUC submits that applications regarding the lawfulness of any proposed treatment, or withdrawal of treatment or care, should be made to no lesser forum than the High Court.

Non-treatment and neglect

71. The MIB provides for punishment if a person “ill treats or wilfully neglects” a mentally incapacitated person in his or her care. However it allows withholding or withdrawal of food and fluids, with the purpose of ending life. Starving and dehydrating a vulnerable person to death is in itself “wilful neglect.”

72. We note that Professor Peter Millard, formerly Eleanor Peel Professor of Geriatric Medicine at St George’s Hospital, London and past President of the British Geriatric Society, has warned against the assumption that requests for non-treatment in advance directives will necessarily result in death. In some cases patients could survive to suffer “a lengthy, painful ... bedridden existence, precisely what they sought to avoid.” (press statement, 18 April 1995). This danger should dispel any notion that some may have that legally-binding advance refusals would, overall, result in clearing hospital beds.

Euthanasia by denial of sustenance

73. Many people concerned about human rights, medical ethics and the rights of the elderly and disabled have over many years continually voiced their opposition to the withholding or withdrawal of nutrition and hydration from a patient so as to cause the patient’s death.

74. In an open letter published in the *Daily Telegraph* in July 2001, 11 respected medics and medico-legal lawyers said that:

“... the withdrawing and withholding of treatment from patients, particularly hydration and nutrition, is a matter of prime public concern.”

75. As we said in our submission to the House of Lords Select Committee on Medical Ethics:

“Giving food and water to people is about as basic a kind of care as we can give them, the bottom line of any expressions of equal concern and respect. Just as we do not define hunger and thirst as pathologies or clinical conditions, so we do not normally define the giving of food and water as treatments, even if it requires some medical assistance. It is not, after all, aimed at preventing or curing illness, retarding deterioration, or relieving pain and suffering. It is simply meeting a basic human need like sanitary care and protection from exposure.”

76. As we continued in our submission to the Select Committee:

“even if artificially delivered sustenance is regarded as ‘medical treatment,’ it is hard to see how this could be regarded as ‘extraordinary’ (and therefore optional) care, since it is neither futile nor is its provision generally burdensome relative to its benefits.”

Where it is futile—ie it is no longer effective as a means of nourishing the person—or does impose undue burdens on a particular patient, it may of course quite properly be withdrawn or withheld, and as we have noted, the same would apply to the oral provision of food and fluids.

77. “It is ironic that the only reason that tube-feeding has been identified as ‘treatment’ has been so that it can be withdrawn.” PVS expert Dr Keith Andrews, (1995) 311 BMJ 1437 (letters).

78. We note that the Select Committee on Medical Ethics did not support the idea of placing *Bland* on the statute book. In April 2000, government minister Yvette Cooper said:

“As a result of the strongly held views expressed in that consultation [*Who Decides?*], the Government decided not to put the *Bland* judgment, which is in case law, on the statute book.”⁷⁴

We support this position, and remain wholly opposed to putting *Bland* into statute.

79. Yet while the draft MIB does not explicitly enshrine *Bland* in statute, it would go considerably beyond *Bland* in some of its effects. In *Bland*, tube-feeding was defined as a medical treatment, which could be withdrawn if regarded as futile. The draft MIB does not define tube-feeding as medical treatment, but it makes any “treatment” done by a “person providing health care” refusible, either by a donee of LPA (section 10(3)) or by an AD (section 23(1)(a)). Thus it would seem that a “blanket” refusal of treatment might prevent health care providers from doing anything described as a “procedure.” This might include hygiene, hydration by drip, spoon-feeding, giving sedatives or pain-killers, turning immobile bed-bound patients, etc. (see 50(1): “In this Act . . . ‘treatment’ includes a diagnostic or other procedure.”)

80. Also, we fear that the enactment of the MIB as it stands would attack the ability of doctors to “force feed” anorexic patients, since the Bill is liable to be interpreted as exalting the patient’s apparent wishes over the licence—and moral responsibility—of doctors to act in such circumstances. If legally binding advance refusals lead to the loss of such lives, they will become instruments of tyranny over doctors and patients, rather than of “autonomy.”

The Government and euthanasia

81. Euthanasia advocates have long suggested that lethal injections should be preferred to starvation and dehydration. As long ago as 1984, pro-euthanasia bioethicist Dr Helga Kuhse said:

“If we can get people to accept the removal of all treatment and care—especially the removal of food and fluids—they will see what a painful way this is to die and then, in the patient’s best interests, they will accept the lethal injection”.

82. The cruelty of mass euthanasia by starvation and dehydration would almost certainly lead to pressure for what is euphemistically called “terminal sedation”—lethal injections under the guise of palliative care. The euthanasia lobby must be denied the fertile ground of “passive” euthanasia found in the draft MIB upon which it could wage a renewed battle for “active euthanasia”.

83. It is no surprise that the pro-euthanasia Hemlock Society of Colorado (now euphemistically renamed “End-Of-Life Choices”) endorses death through starvation as a form of euthanasia.

84. It is interesting to note that the concepts of living wills was invented by an attorney for the Euthanasia Educational Fund, Louis Kutner⁷⁵ and first proposed by Kutner at a meeting of the Euthanasia Society of America in the late 1960s⁷⁶; that living wills were introduced into the United Kingdom by the Voluntary Euthanasia Society (VES) during the 1980s⁷⁷; and that the VES promoted a 1983 private members’ bill in the House of Lords entitled the Medical Treatment (Advance Directives) Bill.

85. The proposals in the draft MIB are in many respects similar to the proposals contained in the Law Commission 1995 Report on Mental Incapacity. It is important to note that the then Conservative Government refused to implement this report because it would weaken the legal prohibition on euthanasia:

“The Government have decided not to legislate on the basis of the Law Commission’s proposals in their current form . . . The Government wish to emphasise that they fully support the views of the House of Lords Select Committee on Medical Ethics that euthanasia is unacceptable and have no plans to change this policy.”⁷⁸

86. Paragraph 2.6. of the government’s green paper *Who Decides?* stated:

“The Government has always emphasised that it does not accept that the individual’s right to determine the treatment he or she is prepared to accept or refuse extends to any action deliberately taken to end the patient’s life.”

87. In October 1999, the present Labour government published its proposals to reform the law on mental incapacity, which have now been enshrined in the draft MIB. At that time it stated that:

“the Government wishes to make absolutely clear its complete opposition to euthanasia which is, and will remain illegal”.

88. The Government has claimed that killing by neglect is not euthanasia because it defines euthanasia very narrowly as “a deliberate intervention undertaken with the express intention of ending a life.” It claims that killing by withholding or withdrawing food and fluids is not euthanasia because it involves withholding or withdrawing “treatment” rather than initiating lethal treatment.

⁷⁴ Hansard, 14 Apr 2000: column 646.

⁷⁵ Peter Jeffery, *Going against the stream: Ethical aspects of ageing and care*, Gracewing, UK, 2001, p.97.

⁷⁶ <http://www.endoflifeissues.org.uk/livingwill.asp>

⁷⁷ *Ibid.*

⁷⁸ Hansard, 16th January 1996, columns 487-88.

89. This is untenable. Even in *Bland*, one judge (Lord Mustill) went so far as to declare the practices of euthanasia by commission and omission ethically indistinguishable. If the government was genuine in its opposition to euthanasia, it would recognise that the deliberate omission of tube-feeding to patients is euthanasia and it would ensure that the practice was outlawed. Killing by starvation and dehydration is just as much euthanasia as giving a lethal injection.

90. It is the intent to cause death, not the method chosen to bring it about that is important.⁷⁹

91. If the Government is truly serious in its stated opposition to euthanasia, and wants to advance the true best interests of people who are mentally incapacitated, it should make it clear that whatever a person may have requested in an advance decision, there is no obligation on doctors to carry out unethical acts such as depriving a person of food or fluids or appropriate treatment. Incapacitated people, like all human beings, are entitled to the best available treatment, given in their clinical best interests.

92. It is imperative that the Government should ensure that any legislation it proposes does not allow omissions of treatment or care which are undertaken with the intention that death results. As we have noted, it was precisely out of concern not to weaken the current law in this respect that the previous Government rejected the Mental Incapacity Bill as drafted by the Law Commission.

93. That their analysis was correct is surely borne out by the fact that a mental incapacity bill has always been keenly promoted by the Voluntary Euthanasia Society:

“We welcome today’s draft legislation on mental incapacity.”⁸⁰

94. The Government’s link with the euthanasia agenda was made particularly clear in a consultation it conducted last year on advice leaflets for decision-making regarding the mentally incapacitated. The leaflets are meant to “set . . . the scene for new legislation” and give “guidance [which] will evolve over time, to reflect future changes in law and policy affecting people who lack capacity.”⁸¹ One of the leaflets referred readers to the Voluntary Euthanasia Society (VES) for information on “living wills” and advance directives, despite the fact that such advice is available from other organisations which do not advocate euthanasia.

95. In answer to the question “What rights does a VES Living Will give me?” the VES website states “In a Living Will you can set out what medical treatment you wish to refuse in such circumstances—for example you may not wish to be resuscitated or *tube-fed*.” [our italics]. The VES Living Will itself states: “I am not to be subjected to any medical intervention or treatment aimed at prolonging or sustaining my life [and] any distressing symptoms (including any caused by lack of food and fluid) are to be fully controlled by appropriate analgesic or other treatment, even though that treatment may shorten my life.”

96. If the government is really against euthanasia as it claims, it should explain why it is sending people for advice to an organisation that wants to legalise killing.

MISCONCEPTIONS REGARDING THE BILL

97. The “Making Decisions Alliance” has welcomed the draft MIB. However, a number of claims by the Alliance are erroneous or at best questionable:

98. “There is no legal framework in England & Wales covering mental incapacity—that is, about who can make decisions” and “At the moment there is no legal definition of ‘capacity’. This means that people without capacity do not have their rights protected because the law does not fully recognise their particular status and situation. It also means that it is very difficult to decide who has capacity and who does not when a decision has to be made.”⁸²

This is false: in *Re: B*⁸³, Butler-Sloss P said that the general law on mental capacity was clear and the principles established in a series of cases during the 1990s. Butler-Sloss also said in *Re: MB*⁸⁴:

“In *Tameside and Glossop Acute Services Trust v CH* [1996] 1 FLR 762 . . . Wall J . . . set out the general principles which govern non-consensual treatment and applied the three part test, (the C Test), set out by Thorpe J in *Re C*”.

The legal test for competence in adults set out by Justice Thorpe’s decision in *Re: C*⁸⁵ is:

“first, comprehending and retaining information, secondly, believing it and thirdly, weighing it in the balance to arrive at a choice”.

⁷⁹ *R v Gibbins & Proctor* 13 Crim App Rep (1919) 134.

⁸⁰ Deborah Annetts, chief executive of the Voluntary Euthanasia Society, 27 June 2003, <http://news.bbc.co.uk/1/hi/health/3023534.stm>

⁸¹ Lord Chancellor’s Department Central Office of Information, 10 April 2002.

⁸² www.makingdecisions.org.uk

⁸³ [2002] 1 FLR 1090 at 1095.

⁸⁴ [1997] 8 Med LR 216.

⁸⁵ *Re C (Adult: Refusal of Treatment)* [1994] 1 WLR 290.

⁸⁶ *Masterman-Lister v Brutton and Co and another* [2002] EWCA Civ 1889.

Also, reference can be made to *Masterman-Lister*⁸⁶:

"The judge ruled that the court should only take over the individual's function of decision making when it was shown on the balance of probabilities that such person did not have the capacity sufficiently to understand, absorb and retain information, including advice, relevant to the matters in question sufficiently to enable him or her to make decisions based upon such information . . . The burden of proof rested on those asserting incapacity . . . if there was clear evidence of incapacity for a considerable period then the burden of proof might be more easily discharged . . . following the implementation of the Human Rights Act 1998 in order that a party was not deprived of his civil rights by being treated as a patient, the court should always, as a matter of practice, at the first convenient opportunity, investigate the question of capacity whenever there was any reason to suspect that it might be absent. That meant that, even where the issue did not seem to be contentious, a district judge who was responsible for case management would almost certainly require the assistance of a medical report before being able to be satisfied that incapacity existed."

Even one of the members of the Making Decisions Alliance (Harry Cayton, chief executive of the Alzheimer's Society) has said:

"The mental health act provides a framework in which medication can be given to people who cannot give consent."⁸⁷

Both the Department of Health and the BMA have published advice on the assessment of capacity.

99. "Currently, the law suggests that a person either has full capacity or no capacity."⁸⁸ Yet the common-law test for capacity (cf *Masterman-Lister* et al) specifies that the test is whether the person has capacity "sufficiently to understand, absorb and retain information, including advice, *relevant to the matters in question sufficiently to enable him or her to make decisions based upon such information*" [our italics]. (This further proves our point, made in relation to best interests, that the flexibility of case-law currently obviates the need for statutory criteria in relation to mental incapacity law.) The court in *Re: MB* held that:

"the graver the consequences of the decision, the commensurately greater the level of competence was required to take the decision."

Butler-Sloss P said in *Re: MB*:

"A person lacks capacity if some impairment or disturbance of mental functioning renders the person unable to make a decision whether to consent to or to refuse treatment: That inability to make a decision will occur when (a) the patient is unable to comprehend and retain the information which is *material to the decision, especially as to the likely consequences of having or not having the treatment in question*. (b) . . ." [our italics]

100. . . . professionals are often unsure about what the law allows them to do to ensure the patient gets the necessary treatment. As a result, professionals are at risk of being accused of malpractice; while patients are vulnerable to abuse. New legislation will therefore protect people who may not have capacity, empower people who have difficulty making or communicating decisions and, it will also help protect professionals in carrying out their duties."⁸⁹ Yet Lord Brandon of Oakbrook said in *Re: F*:

"The common law would be seriously defective if it failed to provide a solution to the problem created by such inability to consent. In my opinion, however, the common law does not fail."

Yet under the draft MIB, professionals will be allowed or forced to commit what is currently regarded as malpractice; patients will be vulnerable to abuse; and professionals will be dispensed from carrying out their duties, *viz*, to act in the best medical interests of patients to whom they have an ethical and legal duty of care. Furthermore, even one of the members of the Alliance (Action on Elder Abuse) has asserted that:

"[m]ost cases of elder abuse in Britain take place in the victim's own home and are perpetrated by family or paid carers . . . the situation is an open book for abuse. There is no requirement for carers to be trained at all."⁹⁰

Does Mr. Fitzgerald realise that a donee of a lasting power of attorney—who may well have power over an elderly person's care—will also not be required to be trained?

101. "The law also fails to protect carers and professionals who may need to make decisions on behalf of someone else."⁹¹ Yet under the draft MIB carers and professionals would not be protected from being forced to do things which are currently regarded as medically negligent. The carer or professional may want to preserve the person's life and health but the advance decision or power of attorney may instruct that the person not be given sustenance or life-sustaining treatment.

102. One of the Alliance's key concerns is that "families and friends have no legal right to be involved in

⁸⁶ *Masterman-Lister v Brutton and Co and another* [2002] EWCA Civ 1889.

⁸⁷ <http://www.davesheppard.co.uk/Incapacity.htm>

⁸⁸ <http://www.makingdecisions.org.uk/MDA—Factsheet%204.pdf>

⁸⁹ <http://www.makingdecisions.org.uk/MDA—Factsheet%202.pdf>

⁹⁰ The *Observer*, 21 July 2002.

⁹¹ <http://www.makingdecisions.org.uk/MDA—Factsheet%205.pdf>

making decisions on important welfare and medical matters on behalf of someone who does not have capacity.” The Alliance commissioned a poll conducted by NOP which found that “98 per cent think that their partner should have the right to be involved in making these decisions.” SPUC believes that this concern can be met by giving next of kin a statutory right to be consulted, but not the power to override a doctor’s responsibility to make judgements in the best clinical interests of the patient. In brief, the nearest and dearest to the patient should have the right to be involved with but not to replace the doctor.

103. The Alliance claims that it is the current situation whereby people in Scotland have a mental incapacity act (the Adults with Incapacity (Scotland) Act) people in England, Wales and Northern Ireland do not. However, it is not uncommon for legislation in England and Wales to differ from that in Scotland and in Northern Ireland, and there are good grounds for maintaining this state of affairs. This approach is particularly appropriate in the context of controversial ethical issues, so that recognition and respect for cultural factors (such as moral and religious viewpoints) may be maintained. Tony Blair the prime minister has said:

“Scotland and Northern Ireland need not necessarily be treated in the same way across the various programmes for devolution. One of the points of devolution is that what happens in Northern Ireland or in Scotland is a matter of debate and can be decided in different ways.”⁹²

104. “A functional approach [to assessing capacity] also means that we should not impose our own values. For example, what you perceive to be an unwise or irrational decision may be the preference of that person and their choice should be respected.”⁹³ Yet under the MIB, the values of others will be imposed upon others in the subjective (and in the case of advance decisions, unverifiable) interpretation of patient’s wishes and feelings.

105. “We want a new rights-based legal framework on mental capacity . . .”⁹⁴ Yet leading public lawyer Richard Gordon QC has concluded that the draft MIB is incompatible in several significant ways with the European Convention on Human Rights.

106. “Millions of people who may have difficulty making decisions and need help to do so at some stage in their life are currently unprotected by any legal safeguards to ensure their views are respected.”⁹⁵ The Alliance here has made a sweeping statement which fails to remember the safeguards laid down by case-law, in particular those relating to advance refusals of treatment as dealt with in *Re: AK*.

107. Regarding the provisions of the Bill on advance decisions the Alliance has said “Although advance statements are sometimes concerned with the refusal of life-sustaining procedures in the event of terminal illness, they have nothing to do with euthanasia or suicide.” This is disingenuous. The provisions of the Bill do not stipulate that advance decisions would apply only in cases of terminal illness. Rather, the trigger for an advance decision to come into effect would simply be mental incapacity.

108. Richard Kramer, co-chair of the Alliance was quoted in *Tribune* magazine of 22 August 2003 as stating:

“There is a vast difference between deliberately intervening to end someone’s life—which is illegal—and withdrawing treatment in cases where there is no realistic prospect of recovery now or in the future.”

This statement is disregards the context of the Bill: firstly, the Bill would allow the withdrawing not just of treatment but of food, fluids and care from patients. Secondly, the Bill does not just apply to the chronically mentally incapacitated, as the Bill’s states clearly in clause 1 that “a persons lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment or a disturbance in the functioning of the mind or brain” and that “It does not matter whether the impairment or disturbance is permanent or temporary.” A person therefore who was unconscious for, say, two weeks, might be dehydrated to death, if it was asserted that the person directed the withdrawal of treatment in an advance decision or power of attorney.

109. Mr Kramer also states that:

“This legislation will strengthen the role of carers’ right to be involved in treatment and, if anything, strengthen safeguards, as the decision will not be made by professionals alone.”

However, as cited above, Richard Gordon QC has stated:

“It is also, to say the least, a temporary impediment to access (and therefore, also a breach of Article 6) for obviously interested parties (such as those exercising general authority under clause 6) to require the leave of the Court under clause 40(2) and for there to be a general prohibition against applications without leave under clause 40. *A fortiori* given the fact that there is no statutory mechanism for the involvement of the Court at all.”

Parties exercising general authority are defined under clause 6 as “any person . . . providing any form of care for another person [who] lacks . . . capacity in relation to the matter in question.” Therefore the Bill will deny carers a right to challenge treatment decisions in court.

⁹² *Hansard*, 4 March 1998; Vol 307, c 1056.

⁹³ <http://www.makingdecisions.org.uk/MDA—Factsheet%203.pdf>

⁹⁴ <http://www.makingdecisions.org.uk/MDA—Factsheet%205.pdf>

⁹⁵ <http://www.makingdecisions.org.uk/MDA—Factsheet%2013.pdf>

110. Mr. Kramer also states:

“The Alliance supports the current law regarding these decisions where doctors must get permission from the High Court before taking action. We are happy with that and the Bill in no way endangers any of the current safeguards in place.”

However, at present this “safeguard” only applies to permission to withdraw assisted food and fluids from patients and only then from patients regarded as being in a permanent vegetative state (PVS). Under the Bill even this “safeguard” could be lost where an advance decision or lasting power of attorney was operative and may well be lost even where an advance decision or lasting power of attorney was not operative. Although the legality of the withdrawal of assisted food and fluids from incapacitated non-PVS patients is disputable, there are no “current safeguards” (in terms of obligatory Court permission) for incapacitated non-PVS patients against being “endanger[ed]”.

David Congdon, head of campaigns and policy at Mencap, a member of the Alliance, has said to deny treatment to someone because they had a disability was “an assault on their basic human rights”. SPUC agrees, yet the obligatory nature of advance and proxy decision-making under the MIB would create such an evil. As Lord Jauncey of Tullichettle warned in *Re F*:

“I should like only to reiterate the importance of not erecting such legal barriers against the provision of medical treatment for incompetents that they are deprived of treatment which competent persons could reasonably expect to receive in similar circumstances. The law must not convert incompetents into second class citizens for the purposes of health care.”

111. The Alliance’s answers to the question “So why doesn’t the government introduce legislation?” is “legislation in other areas may be considered to be of greater priority” and “discussion about decision making can lead to complicated ethical and moral debates.” SPUC agrees.

The Government’s legislative plans

112. “Clearly, legislative changes can only be made when parliamentary time allows.” *Making Decisions*, October 1999.

113. The Government: has already experienced great problems in the passage of the not-unrelated Mental Health Bill. Also, it is already seeking parliamentary time for major primary legislation on a whole of controversial issues, including (but not restricted to):

- reform of the House of Lords;
- abolition of the post of Lord Chancellor;
- a new Supreme Court;
- judicial appointments;
- civil registration of same-sex partnerships;
- deportation of asylum seekers;
- hunting;
- “gender recognition” (transsexuals);
- identity cards;
- undergraduate top-up fees;
- reduction of the number of Scottish MPs; and
- corruption.

114. In a speech at the Joint Conference of the Law Society and the Royal College of Psychiatrists in June 2002, Rosie Winterton MP, Parliamentary Secretary at the Lord Chancellor’s Department said:

“We remain committed to introducing legislation [on mental incapacity] as soon as parliamentary time allows, but I am sure you are aware of how busy the current legislative schedule is.

115. Such a complex and controversial Bill as the draft MIB will be difficult to pass through Parliament when there is already precious little parliamentary time for the government to deal with its existing legislative priorities.

116. Lord Irvine of Lairg, the Lord Chancellor, told the House of Lords in December 1997 that “[The Government] is . . . determined that any [mental incapacity law] reform should command the widest possible public support.”

117. The Government’s proposals do not command the support of SPUC’s members, who number 45,000 members throughout the United Kingdom, include a wide cross-section of the public and include those vulnerable under the Bill, as well as doctors (some of whom are experts in fields relating to mental incapacity), nurses, carers etc.

SPUC has concluded therefore that:

- the legal status quo regarding protection for the mentally incapacitated is greatly preferable to the regime proposed by the Bill. As Richard Gordon QC has stated: “The fact that the current state of the law is, in relation to incapacitated persons, inadequate does not, of course mean that the intended statutory reforms contained in MIB are ECHR (European Convention on Human Rights) compliant.”
- the MIB will radically distort the whole medico-legal regime for the welfare of vulnerable patients.
- the Bill is so extensively flawed and problematic that it should be withdrawn as it worsens, rather than improves, the protection afforded to vulnerable patients.

August 2003

107. Memorandum from the Society for the Protection of Unborn Children Bioethical Advisory Team, Dr John I Fleming and Greg Smith (MIB 890a)

INTRODUCTION

The Society for the Protection of Unborn Children (SPUC) exists to promote the inviolable and inalienable right to life of all members of the human family from the first moment of human existence (fertilisation) until natural death. SPUC has, therefore, an interest in testing pieces of public policy against universal standards of human rights to see whether such public policy is in accordance with those standards and that the rights of the most vulnerable members of our society are protected both in law and in practice.

While SPUC welcomes the opportunity that it has been given to comment on the Draft Mental Incapacity Bill (*the Draft*), we are concerned that the time for formulating sensible comment is so short and that the summer holiday time has been chosen as the time when such formulations must be made. Sound democratic practice requires that there be generous time for public consultation since public consultation is not merely a part of the process to which lip service is given, but is essential to that process by which laws are made for the common good.

It is beyond the scope of this submission to fully elaborate philosophically the ethical considerations which are fundamental to the way in which a just and democratic society should honour its obligations where end-of-life decisions are to be made for patients who are no longer able to answer for themselves. We will, however, identify those fundamental ethical considerations with sufficient specification to enable judgments to be made as to whether or not *the Draft* is in a satisfactory condition to be put to the Parliament as the basis for debate and final enactment as law.

The Draft represents an attempt to codify, in law, a legal process in which decisions can be made about the medical treatment of two broad classes of human beings:

1. Those who have lost mental capacity at some point in their lives due to injury or a disease state; and
2. Those whose lack of capacity has been present since birth.

The Draft also provides “recourse, where necessary and at the appropriate level, to a court with power to deal with all personal welfare (including health care) and financial decisions on behalf of adults lacking capacity.” [Cf The Explanatory Notes].

In the case of those who have lost mental capacity having once had it, two principal ways are described by which someone can exercise some control over the decisions made on their behalf when they become unable to answer for themselves. One is by an advanced decision as set out in *the Draft* in clauses 23-25; the other is by the donor person (P) conferring a lasting power of attorney on another (donee) or others (donees) such that the donee or donees have authority to make certain decisions on P’s behalf and within the scope set out in *the Draft* in clauses 8-13. Also, the court may appoint a deputy who may give or refuse consent to the carrying out or continuation of a treatment by a person providing health care to P: Clauses 16-17.

RELEVANT ETHICAL CONSIDERATIONS

Rather than repeat work that has already been done and to which the Parliament already has access, we commend the work of John Keown and Luke Gormally, (1999) “Human Dignity, Autonomy and Mentally Incapacitated Patients: A Critique of *Who Decides?*”. The outline of the ethical and legal considerations involved in how we deal with issues connected with persons who are mentally incapacitated remains as valid today as when it was written. A copy is provided for convenience.

HUMAN DIGNITY

Every human being, that is every member of the human family, is entitled to have recognised his or her fundamental inviolable and inalienable human rights based upon the recognition of the inherent dignity of the human being. The dignity of a human being is not something attributed to a human being based upon "quality of life" considerations. The dignity or worth of a human being is intrinsic.

So says the *Universal Declaration of Human Rights* proclaimed by the General Assembly of the United Nations on 10 December 1948.⁹⁶ *The European Convention on Human Rights* builds upon the universal moral commitments of the *Universal Declaration of Human Rights* by "taking the first steps for the collective enforcement of certain of the Rights stated in the Universal Declaration"⁹⁷.

Since *The European Convention on Human Rights* is a specification of the *Universal Declaration of Human Rights* then this submission will refer to both documents since all countries of the European Union are bound, in different ways, by both documents.

THE INALIENABLE RIGHT TO LIFE

Specifically, then, the following matters are the benchmark against which *the Draft* is to be judged in this submission.

1. Everyone has the inviolable and inalienable right to life. The right to life is, then, a right of which I cannot be deprived and nor may I deprive myself of it.⁹⁸
2. The only exception to 1. above is when a person is deprived of his or her life intentionally "in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law".⁹⁹
3. Where inherent dignity and fundamental human rights are concerned, they apply equally to all members of the human family "without distinction of any kind".¹⁰⁰

It is an offence against justice and therefore not permissible to kill a human being because his or her life is judged to be without human value or be in some way not a life worth living. It may be that a person has experienced a loss of dignity in the sense that he or she no longer has the powers and abilities they once had to live life the way that he or she would like to live it. But that loss of dignity does not mean that that person has *no value* since there is a dignity intrinsic to the human being which is only extinguished at death. By resort to such jurisdiction the court is empowered to protect the human dignity and rights of those individuals who are so disabled that they cannot by themselves protect their own dignity and rights. This is a value which Brennan J said in *Marion's Case* (*supra*):

underlies and informs the law: each person has a unique dignity which the law respects and which it will protect. Human dignity is a value common to our municipal law and to international instruments related to human rights. The law will protect equally the dignity of the hail and hearty and the dignity of the weak and lame; of the frail baby and of the frail aged; of the intellectually able and the intellectually disabled . . . our law admits of no discrimination against the weak and disadvantaged in their human dignity. (*supra* at 266)¹⁰¹

Suicide is also not legally permitted (and cf s.2(1) of the *Suicide Act 1961*) since the right to life is inalienable. Given the overwhelming weight of evidence that suicide is strongly associated with debilitating psychiatric conditions the State does well when it refuses to prosecute someone for attempted suicide. The removal of criminal sanctions against attempted suicide does not constitute in itself a "right to suicide" as some have wrongly concluded.

WHAT IS SUICIDE?

Suicide occurs when a person deliberately and intentionally seeks his or her own death either by a direct act or by omission. Suicide is nearly always associated with the "despair" that comes from a major psychological illness (frequently anxiety and depression). Whether or not the person is psychologically competent it is always suicide, or attempted suicide, when a person intentionally seeks death through either an act that he or she does to himself or herself or by refusing to accept something necessary to sustain life such as a life sustaining medication or food and water. Assistance in suicide occurs when one person provides the suicidal one with the means to commit suicide. It becomes euthanasia when that person performs the act necessary to bring about the death of the suicidal one. It is either assisted suicide, or even in some cases euthanasia by omission, when someone who has a duty of care and who could act to prevent the death of the person refuses to do so with the intention that the suicidal one dies.

⁹⁶ Preamble to the *Universal Declaration of Human Rights*.

⁹⁷ Preamble to the *The European Convention on Human Rights*.

⁹⁸ Article 2(1), *The European Convention on Human Rights*.

⁹⁹ Article 2(1), *The European Convention on Human Rights*.

¹⁰⁰ Article 2, *Universal Declaration of Human Rights*.

¹⁰¹ *Secretary Department of Health and Community Services v. J.W.G. and S.M.B.* ((1991–92) 175 CLR 218—*Marion's Case*: See also Halsbury's *Laws of England* 4th Ed. para. 901).

It is neither assisted suicide nor euthanasia when the person with the duty of care withholds or withdraws treatment that is either futile or burdensome disproportionate to benefit. When medical treatments can do no more than maintain a patient with a precarious and burdensome hold on life it is ethically appropriate to withdraw or withhold those treatments and provide all such other treatments which one would ordinarily provide to a person as well as those treatments directed to the alleviation of pain and the maximisation of patient comfort.

AUTONOMY

Human beings have the capacity to make free choices and to determine what acts they will or will not do. The exercise of autonomy is not an absolute. It is not permissible to appeal to autonomy as a justification for killing the innocent or for doing any one of a number of things which human beings can do and have done which are destructive of self and others. "Autonomy itself as a capacity is to be valued precisely in so far as its exercise makes for the well-being and flourishing of the human beings who possess it."¹⁰² An act or omission freely chosen is not to be admired merely because it has been freely chosen. Such free choices are to be admired and respected in so far as they respect human dignity and the fundamental human rights which derive from that dignity.

Nor is autonomy to be thought of as a baton in a relay race which can be delivered whole and entire to another. I am the only one who can fully exercise my autonomy. I cannot exercise the autonomy of another, but I can, at that person's invitation, or by reason of my relationship to another (parent to child) exercise my own autonomy in the best interests of another, best interests being understood objectively and in a way that fully respects human dignity and human rights.

SUICIDE AND LEGAL CONSIDERATIONS

If P, a person in good health, but who desires to commit suicide, made an advance decision that if he were found unconscious as a result of a suicide attempt, no life saving treatment was to be administered, then presumably by operation of Clauses 24 and 25, the health carer's desire to save P's life would be over ridden and any treatment in defiance of the advance decision would be unlawful.

This is a serious infringement on ethical medical practice. Basing his opinion on studies which consistently show that the vast majority of successful suicides are performed by people suffering mental illness, usually depression, Glanville Williams has stated that it is reasonable to presume that persons found to be attempting suicide, about whom nothing is known of their state of mind, are suffering a mental disorder. He continues:

Anyone is entitled at common law to apprehend a person who is mentally disordered and who is a danger to himself or others, the purpose of the apprehension of course, being to get him to a doctor. Unfortunately, a limitation of this rule is that the person detained must actually be mentally disordered, so if the person attempting suicide turns out to be *compos mentis* it seems that the detention is unlawful, and constitutes at least the tort of assault and false imprisonment.¹⁰³

TWO NORTH AMERICAN CASES

Williams then referred to an American case which decided that administering an antidote to a would be suicide was lawful¹⁰⁴, and a Canadian case where it was held that a would be suicide who forcibly resists an attempt by a police officer to stop him can be convicted of assaulting the officer in the execution of his duty¹⁰⁵.

TWO AUSTRALIAN CASES

Two Australian cases support the interventions of health carers in saving the lives of persons attempting suicide. In one such case, Graham Kinney had been admitted to the Emergency section of St Vincent's Hospital, Melbourne, after attempting suicide by drug overdose while on bail after being charged with the murder of his mother-in-law. Doctors had caused substantial bleeding when they inserted an instrument down his throat to assist breathing. Doctors needed to find the source of bleeding, as blood supplies for transfusion were limited. His wife applied for an injunction to restrain doctors from conducting exploratory surgery to locate the source of bleeding. Kinney's wife argued that he should be allowed to die as he had

¹⁰² John Keown and Luke Gormally, 1999, "Human Dignity, Autonomy and Mentally Incapacitated Patients: A Critique of *Who Decides?*", copy attached, at page 7.

¹⁰³ Glanville Williams, *Textbook of Criminal Law*, London: Stevens & Sons, 1983, p.616.

¹⁰⁴ *Meyer v Supreme Lodge KP* (1904) 70 NE (New York).

¹⁰⁵ Dietrich (1978) 39 CCC (2d) 361.

leukaemia and wished to die. To bring him back from the brink of death she argued would, in the circumstances, be cruel and inhuman. Common law principles applied as Kinney had made no direction under the Medical Treatment Act. Fullager J refused the application for an injunction:

It would require very powerful considerations indeed to persuade the court to extend that remedy to prevent doctors from saving the life of a person.

This is especially so in the light of the Act of Parliament to which Mr Wheeler drew attention viz. The Medical Treatment Act of 1988. Further I think even more powerful considerations would be required to persuade the court to grant an injunction when the preventing of the medical or surgical treatment amounts to carrying into execution the attempted suicide of the person concerned. To grant the injunction would be to assist the person to complete his suicide.¹⁰⁶

In another case Lee J of the New South Wales Supreme Court refused a prisoner, Peter Schneidas, on a hunger strike in an advanced stage of starvation caused by his refusal to take food, an injunction to restrain doctors on behalf of the Corrective Services Commission from administering food, drink or any other form of nourishment to him without consent.

Since Schneidas was in the course of attempting to commit suicide, which was still a crime in NSW, His Honour said:

He comes to this Court inviting me, in effect, to aid and abet him in the commission of that crime by removing an obstacle which stands in the way of him carrying out his intention. I firmly refuse to do so. I make it clear that I would not participate to any extent at all in the wilful destruction of the plaintiff's life; to injunct those who would save his life, would make me a participant.¹⁰⁷

A DIFFERENT APPROACH IN BRITAIN

The case of Tony Bland is well known. The decisions made in this landmark case were the culmination of a series of decisions whereby British Courts have significantly compromised the law's adherence to the principle of the inviolability and inalienability of the right to life, a principle which Britain is bound to uphold in conformity with *The European Convention on Human Rights*.

In the Bland case, *Airdale NHS Trust v Bland* [1993] AC 789, the court, while still holding that it remains murder for a doctor to intentionally kill a patient by an act, nevertheless held that, in at least some circumstances, a doctor may (even must) intentionally terminate a patient's life by deliberate omission.

Donald Robertson has summarised the House of Lord's findings or assumptions in Bland as follows:

- Anthony Bland is alive.
- The intention (aim or purpose) of the doctors in withdrawing life support systems was to kill Anthony Bland.
- There is a legally significant distinction between acts of commission and acts of omission. Thus, it asserts, it is not authorising euthanasia.
- Anthony Bland's existence in PVS was not a benefit to him. It was not in his best interests to continue life-sustaining care or treatment and the physicians were not entitled to continue the medical care.¹⁰⁸

The Bland case has also significantly reinterpreted the notion of "best interests", such that the "best interests" of a patient may now include seeking a patient's death by removal of life sustaining measures from a non-dying patient.

No wonder, then, Lord Mustill observed in Bland [1993] AC 789 at 887 that the Bland case has left the law in a "morally and intellectually misshapen" state. In such a state all kinds of further legal developments become possible.

So, in a subsequent case where an adult prisoner refused all nutrition, and medical experts agreed he was of sound mind and understood the consequences of his decision, the Home Secretary sought declarations that various Government servants and health carers might lawfully observe and abide by the prisoner's refusal and abstain from providing him with nutrition and hydration by artificial means or otherwise for as long as he retained the capacity to continue his refusal. Thorpe J granted the declarations on the basis that prisoners have the same right to refuse treatment as other persons, although he agreed that it wasn't an absolute right. In contrast to the Australian judges he remarked on the suicide issue:

The second countervailing state interest, preventing suicide, is recognisable but seems to me to be of no application in cases such as this where the refusal of nutrition and medical treatment in the exercise of the right to self-determination does not constitute an act of suicide.

¹⁰⁶ In re Graham Michael Kinney: Application by Tahlia Kinney (Unreported, Vic SC. 23 December 1988).

¹⁰⁷ Schneidas v Corrective Services Commission (Unreported, NSWSC, 8 April 1983).

¹⁰⁸ Donald Robertson, "The Withdrawal of Medical Treatment from Patients: Fundamental Legal Issues" (1996) 70 Australian Law Journal 723 at 728.

Thorpe J had earlier stated, based on the authority of Bland, that:

... a patient who is entitled to consent to treatment which might or would have the effect of prolonging his life and who refuses to so consent, and by reason of the refusal subsequently dies, does not commit suicide. A doctor who, in accordance with his duty, complied with the patient's wishes in such circumstances does not aid or abet a suicide.¹⁰⁹

This is curious. Thorpe J seems to be saying that suicide can only be committed by an act and not by refusal of food and other forms of treatment. But Bland, whose authority he appeals to, was not about that.

Against Thorpe J, John Finnis has observed:

The law firmly and rightly holds that those who have undertaken to provide treatment or nourishment are not absolved from their duty by the patient's adamant refusal if that refusal is either incompetent or unlawful. A refusal which is motivated by suicidal intent is unlawful, even though suicide itself is not a criminal offence; that is why assistance, and agreements to assist, in suicide are serious criminal offences.¹¹⁰

AUSTRALIAN EXPERIENCE WITH ADVANCE DECISION LEGISLATION

There are similarities between the provisions of the Draft Bill and legislation which has been in operation for some years in several Australian States and Territories. The most controversial legislation has been the Medical Treatment Act 1988 (Victoria), which has been largely copied in the Medical Treatment Act 1994 (Australian Capital Territory). South Australia, which sought to cover similar issues in its Natural Death Act, replaced this in 1995 with the Consent to Medical Treatment and Palliative Care Act.

In a recent landmark decision in the Victorian Supreme Court¹¹¹, the Public Advocate had been appointed guardian of a 68 year old comatose patient suffering from dementia. BWV suffered from a progressive and fatal form of dementia, probably Pick's Disease. She had not appeared conscious, or to have had any cortical activity, for approximately three years. She appeared to have no cognitive capacity at all and had no bodily functions, other than those which are reflexive. Further, she appeared to have no conscious perception of input from any of her sensory pathways.

BWV received fluid and nutrition via a percutaneous endoscopic gastrostomy ("PEG") which kept her alive. BWV required full nursing care: she was doubly incontinent; received regular pressure care; was moved into a shower by a hoist; and she received medications, as well as nutrition and hydration, through the PEG. Although the brain stem of BWV continued to function normally, the medical evidence was that the damage to the cortex was irreparable. There was no prospect of any recovery, or improvement of any kind in BWV's condition.

The evidence of the three medical witnesses who examined BWV was that the provision of nutrition and hydration, via the PEG, was futile, in the sense that it had no prospect whatever of improving her condition.

With the support of the woman's family, the Public Advocate sought the following orders:

- (a) provision of nutrition and hydration via a percutaneous endoscopic gastrostomy ("PEG") to BWV constitutes "medical treatment" within the meaning of the term in the *Medical Treatment Act 1988*; and (b) refusal of further nutrition and hydration administered via a PEG to BWV constitutes refusal of "medical treatment", rather than refusal of "palliative care", within the meaning of the *Medical Treatment Act 1988*.
- (b) If the declarations sought were made, the Public Advocate, on behalf of BWV, intended to refuse further medical treatment in the form of the provision of nutrition and hydration via the PEG (subject to satisfying certain other conditions required by the Act). It was expected that BWV would die within one to four weeks of the withdrawal of such nutrition and hydration. BWV subsequently died, as predicted.

Section 3 of the Medical Treatment Act defines "medical treatment" and "palliative care", as follows:

"medical treatment" means the carrying out of—

- (a) an operation; or
- (b) the administration of a drug or other like substance; or
- (c) any other medical procedure—

but does not include palliative care;

"palliative care" includes—

- (a) the provision of reasonable medical procedures for the relief of pain, suffering and discomfort; or
- (b) the reasonable provision of food and water.

Section 4 preserves other applicable laws. It states:

¹⁰⁹ Secretary of State for the Home Department v Robb (1995) 2 WLR 722.

¹¹⁰ John Finnis (1994), "Living Will Legislation" in Luke Gormally (ed) *Euthanasia, Clinical Practice and the Law*, London, The Linacre Centre, 167.

¹¹¹ Gardner: re BWV [2003] VSC 173 (29 May 2003).

4. Other legal rights not affected

1. This Act does not affect any right of a person under any other law to refuse medical treatment.
2. This Act does not apply to palliative care and does not affect any right, power or duty which a registered medical practitioner or any other person has in relation to palliative care.

(3) This Act does not—

- (a) affect the operation of *section 6B(2) or 463B of the Crimes Act 1958* (these provisions are concerned with inciting, or aiding or abetting, another person to commit suicide; and using force to prevent the commission of suicide); or
- (b) limit the operation of any other law.

(4) A refusal of medical treatment under this Act does not limit any duty of a registered medical practitioner or other person—

- (a) to advise and inform the patient or the patient's agent or guardian; or
- (b) to provide medical treatment, other than medical treatment that has been refused.

Morris J found that the administration of nutrition and hydration using a 'PEG' satisfied sub clause (b) of the definition of "medical treatment".¹¹² He went on to consider whether such administration also came within the meaning of "palliative care". He found that:

"the administration of artificial nutrition and hydration, via a PEG, cannot be regarded as palliative care, where that expression is used in its natural sense. Such a procedure is, in essence, a procedure to sustain life; it is not a procedure to manage the dying process, so that it results in as little pain and suffering as possible"¹¹³

Later, to cover his reasoning against appellate correction, he concluded

If my conclusion as to the meaning of the expression "the . . . provision of food and water" is wrong, and instead this expression includes the provision of artificial nutrition or hydration, the question would then arise whether, in the circumstances of BWV, the continued provision of artificial nutrition and hydration was "reasonable". If I was required to answer this question, I would find that the further provision of artificial nutrition or hydration was not reasonable in all the circumstances. In forming this view I would rely upon the evidence of the medical witnesses who observed BWV, the view of her guardian that it would be contrary to her wishes to continue to receive nutrition and hydration through the PEG, her existing condition, the period for which she has been in her existing condition, her prognosis and the fact that continued feeding is doing no more than merely postponing the natural dying process.¹¹⁴

THE DRAFT

Comparing *the Draft* with the ethical principles already identified, and in the light of legal judgements that have already been made in Britain and elsewhere, SPUC finds *the Draft* to be fatally flawed in a number of key respects affecting the inviolable and inalienable right to life.

While there is nothing in *the Draft* which specifically authorises anyone to fail to supply nutrition and hydration to a person who is incapable of supplying these essentials for life to himself or herself, clauses 23 to 25 make numerous references to "treatment", while clauses 24 and 25 refer to "life sustaining treatment". Clause 7 (4) defines life-sustaining treatment, as meaning "treatment which in the view of a person providing health care for P is necessary to sustain life". Clause 24(5) allows P to make an advance decision refusing life-sustaining treatment. "Treatment" is defined in very general terms in the interpretation section (clause 50) as including "a diagnostic or other procedure".

In an important Australian case O'Keefe J stated that "the usual relief sought in England in respect of patients from who artificial feeding, hydration and treatment are sought to be withdrawn, is by way of declaration that "the responsible medical practitioners . . . may lawfully discontinue all life sustaining treatment and medical support measures, (including ventilation, nutrition and hydration by artificial means) designed to keep (the patient) alive in (his or her) existing permanent vegetative state'."¹¹⁵ So it is that the Draft would, under the common law as interpreted in Bland, include the supply of nutrition and hydration under the rubric of "life sustaining measures".

The Draft allows the withdrawal of food and fluids from non-dying patients either by way of an advanced decision or by way of a person exercising a lasting power of attorney. In addition, the court or a court appointed deputy might authorise such withdrawal. In this way *the Draft* provides for assistance in suicide

¹¹² *Pretty v United Kingdom* (Application No. 2346/02).

¹¹³ *Ibid.*, at [81].

¹¹⁴ *Ibid.*, at [95].

¹¹⁵ *Ibid.*, at [95].

and euthanasia by omission. Worse still, the conscientious doctor or other carer might find himself or herself in a position where they are legally obliged to carry out and be party to a patient's wishes which are suicidal. O'Keefe in *Northridge* commented on such cases:

112 The existence of the standard and guidelines and the practice of the court clearly regard the diagnosis of permanent vegetative state as fraught with difficulties and as being one which should be arrived at only after a lengthy period, in which there is no change in the state of consciousness of the patient. Furthermore, the requirement that termination of treatment, artificial feeding and hydration be only with the prior sanction of a High Court judge, is a clear recognition of the right of unconscious patients to have their right to life protected by the full power of the law.

The *Northridge* case is important in that it involves a case of wrong diagnosis by doctors, with almost fatal consequences. A 37 year old patient, John Thompson, was admitted to hospital in an unconscious state after an apparent drug overdose and given intensive care treatment. Within a few days he was written off as a person for whom there was no hope of recovery. Over the objection of the family, antibiotics and feeding were stopped. A direction was given by doctors that the patient not be resuscitated if his bodily functions ceased. The patient's sister applied to the NSW Supreme Court for orders that treatment and feeding be recommenced.

O'Keefe J concluded:

115. Events subsequent to the initial hearings clearly establish that the decision to withdraw treatment and nutrition from Mr Thompson was premature; the prognosis that he would soon die, wrong. The change in his medical treatment and support regime consequent upon the intervention of the court helped to ensure that Mr Thompson not only stayed alive, but improved to the extent demonstrated on video recordings exhibited in the proceedings. Furthermore, the diagnosis and prognosis by Emeritus Professor Lance seems to have been accepted by the hospital and a number of the medical practitioners who had been treating Mr Thompson. These factors highlight the wisdom of allowing a sufficient time to pass between the trauma or other event giving rise to the unconscious state of the patient and the making of a diagnosis of permanent (or chronic) vegetative state, which may be, and in the present case was, a prelude to the withdrawal of treatment, support and nutrition.

116. The material before the court reveals that Mr Thompson has been transferred to a nursing home and that in such an environment he has continued to improve with the aid of appropriate rehabilitative treatment. Counsel for the defendant indicated that it was proposed to maintain appropriate medical and other treatment and support and that there was no longer any question of withdrawal of such treatment and support or of nutrition.

Cases such as this demonstrate the need for great care and caution in dealing with incompetent patients and respecting the patient's right to life by maintaining treatment, nutrition and hydration unless the patient is unable to assimilate them. They also demonstrate the fallibility and sometimes arrogance of members of the medical profession towards incapacitated patients and the danger of giving them immunity over decisions causing the deliberate death of patients. It is ironic that the Director of Public Prosecutions, for good reasons, does not have power to give immunity against prosecutions in advance to allow a husband to assist his wife's suicide, yet under *the Draft*, doctors and others are given such immunity.

The Draft fails to provide protection to patients where it is most needed. The obligation which the State has pursuant to article 2 of The European Convention on Human Rights is to make sure not only that life is not taken intentionally, but also that life sustaining treatment is made available to patients in the best interest of the patient. On these matters *the Draft* not only fails to ensure that those obligations are met, but contrives to provide ways and means so that they are not met.¹¹⁶

RECOMMENDATION

That the Draft Mental Incapacity Bill be withdrawn.

August 2003

108. Memorandum from the Royal College of Speech and Language Therapists (MIB 895)

The RCSLT welcomes the opportunity to comments made on this draft Bill. Speech and Language Therapists (SLTs) are the only registered profession qualified to assess peoples' communication capacity including the use of augmentative and alternative communication methods across all age and care groups.

¹¹⁶ *Northridge v Central Area Health Service* (2000) 50 NSWLR 549 at 568.

Our comments are as follows:

1. We welcome the broad aims expressed in the overview, and the attempt for the Bill to provide a clear informal system to ensure people are able to maintain their maximum level of autonomy.

2. CONSULTATION PROCESS

The consultation process could be strengthened by sending reminders to key stakeholders a week before the end of the consultation period—NICE do this.

Also, is it possible to manage consultations so that they are not occurring during mid July and August or to extend the consultation period till mid September? We have had few responses because of SLTs on holiday or using this time to review their services.

3. THE OBJECTIVES

The objectives of the bill seem reasonably clear however, because it is written within a legal framework is still not easily accessible. It seems sufficient and workable, in that no identifiable gaps (other than those noted below—section 5 and 6) have as yet been noted. Further analysis, discussion and more detailed information about how the Bill is to be operationalised, the requirements for decision makers etc is needed to then consider if it is really sufficient and workable.

Are we correct in assuming implementation of the Bill will be covered in “section 30 Codes of practice”. The draft codes of practice from the Adults with Incapacity—Scotland could be useful when developing these codes. We assume that these codes would be consulted on. The NICE guidelines of schizophrenia, and the National Service frameworks for “mental health” and “older people” would also be a useful source of information.

4. OVERVIEW OF BILL JUNE 2003:

LACK OF CAPACITY RELATES TO EACH DECISION TO BE TAKEN

The single definition of capacity is welcome but it is not clear from the Bill who would carry out this assessment, especially in the assessment of capacity depending on the level and complexity of the decision to be made. It would be important to establish that any person(s) making an assessment and judgement about capacity is suitably qualified to do so.

There may need to be guidance stating the type of decisions that could be made from an assessment of capacity, so that the patient is not subject to unnecessary repeated assessments. This would need to be carried out by a person suitable qualified to assess the communicative demands for the decision to be made as well as the abilities of the client. It would be useful to know what is intended for the statutory and best interest checklists when they will be available? However, we appreciate that this might be within the codes of practice, yet to be developed.

5. THE BILL:

GENERAL AUTHORITY PART 1 SECTION 6

We understand the section to mean “If an adult lacked capacity, treatment could be carried out if it was considered (by the person with general authority) to be in the best interest of the adult and after working through statutory checklists and consulting with others interested in the welfare of the patient”.

There could also be a number of interested others who could be involved. Consultation would depend on the decision maker’s knowledge and understanding of the different disciplines, their roles, accessibility. For example for an adult with dementia and dysphagia (feeding and swallowing difficulties) and SLT would be the only person able to assess both the changes in communication/cognition and the feeding/swallowing difficulties the patient was experiencing, and the medical, ethical and legal aspects to decision making for feeding in the late stages of dementia are complex.

Our concern therefore is that some professionals might be excluded because of the lack of knowledge of the decision maker.

Where there is no formal decision making mechanism is in place, it would be important to secure a multidisciplinary approach to inform the decision making of the person with general authority.

We would suggest that an explicit statutory checklist is developed to include:

- (a) a summary of the process for decision making process/framework
- (b) information about the role /contributions of the different professionals who might be involved.

Information to assist with this checklist might be found in NICE guidelines for schizophrenia, and the National Service frameworks for “mental health” and “older people”, and the Health Professional Council Standards of Proficiency.

7. LASTING POWER OF ATTORNEY PART 1 SECTIONS 8 AND 10

The points noted above would also apply to these sections, since an attorney would be expected to make decisions about health matters after discussing the issues with “all relevant people”. A concern then is how would they know who the relevant people are unless that information is made available to them.

The meaning of the word “instrument” is not clear (section 8.2, and later sections).

August 2003

109. Memorandum from Patient Concern (MIB 882)

INTRODUCTION

Patient Concern welcomes the provisions of the Mental Incapacity Bill. It will reassure patients that they can retain a measure of autonomy when they are at their most vulnerable and help prevent unwelcome decisions made in their “best interests” by medical staff with no knowledge of their choices, values and priorities.

In our response we shall limit ourselves to commenting on the priorities that will affect the majority of the population, namely people who may wish to anticipate the risk of losing their mental capacity. Other organisations have more expertise in the area of mental illness and disability from birth.

Lasting powers of attorney (LPAs)

This is an essential provision in a supposedly patient-centred service. The current system, where it is “good practice” for medical staff to discuss treatment options with close family, works poorly. We have many complaints about resuscitation or life support decisions taken without consultation. Even where those matters are discussed, the decision rests with doctors. As doctors are, quite rightly, dedicated to saving life, this may result in life-prolonging measures that cause extra suffering, which the patient would not have sanctioned.

There are also frequently situations where family members disagree, in which case doctors will normally pursue the life-prolonging course. The LPA provisions will enable us to appoint a trusted person who knows and understands our views on treatment.

Opponents of this legislation state that attorneys with control over financial and welfare matters will have a vested interest in treatment withdrawal for the unfortunate patient. This may be a legitimate worry in the case of a single attorney. We assume that clause 3(b) means that, in the case of two or more attorneys being appointed, decisions on life-sustaining measures could be limited to someone with no say in the patient’s financial affairs. It might be helpful to clarify this point in the legislation.

Clause 4(c). We read this as meaning that the provisions of a valid advance statement would take precedence over the authority vested in an LPA and we fully support this. However, other organisations have read this as meaning the exact opposite, so clarification is necessary. No attorney should be able to override a properly made advance directive.

In order for attorneys to fulfil their obligations in the field of health and welfare, it is essential for them to be able to consult medical records or case conference notes. We currently receive many complaints that staff worry so much about the rules on confidentiality that carers are denied information they may need to look after a patient. It would be helpful if the rights of an attorney to consult all relevant information were enshrined in the Bill.

Clause 30 outlines codes of practice that the Lord Chancellor must prepare, most of them for use “after the event”. We consider that it is equally urgent to make provision for information to be prepared for access by those considering appointing a LPA. Those taking this step must be aware of the serious implications. Patient Concern would see dissemination of such information as one of its prime tasks, but this could not replace an official avenue of advice.

ADVANCE STATEMENTS

Legislation on advance statements is long overdue and simply catches up with the position of such statements in common law. Common law is not sufficient in this instance, as unconscious or terminally ill patients are in no position to pursue their rights through the courts.

Though the good practice guidelines issued by the BMA, GMC etc all state that valid advance statements must be observed, a great deal of confusion still exists among medical professionals. When we speak at conferences, we find that some doctors still insist that they are not legal and can be ignored. We also have

examples where hospital staff have refused to accept an advance statement, even when backed up by the wishes of the family, and have insisted on prolonging the death of elderly people against the wishes they have expressed in advance. Therefore it is a matter of urgency that their status is clarified.

It seems a necessary and logical follow-up to this embodiment in statute that an advance statement made in written or recorded form should be lodged with a central body, preferably the Court of Protection. It would then be a simple matter to check if such a statement is in existence when, for instance, a patient is admitted to hospital in a coma following a road accident. At the moment there is no obligation on hospitals to check or record the existence of an advance statement, let alone any national guideline on what should happen to such a document once produced. This may be a matter for the Department of Health to rectify but, in the meantime, it is all too easy for an advance statement to be overlooked. Providing the machinery to register a document or tape recording does not imply that an oral statement is not valid and this can be made clear. It merely provides a necessary safeguard against any person being able to claim ignorance of an advance statement.

The Bill refers only to advance statements refusing treatment. It should also acknowledge that such a document can be used to state that the patient wishes any reasonable measures to be taken to preserve and prolong life. We understand that doctors cannot be required to provide any treatment they consider inappropriate, but this is covered by the phrase "reasonable measures". The formal recognition of this type of statement would help to allay fears, often voiced by the disabled, that they will be subject to assumptions made about the quality of their life by the able-bodied. It will also mean that the advance statement will direct any decisions made by an attorney who might, at the crucial moment, be subject to outside influences.

Clause 24 (4c) causes us great concern. It is probably impossible to judge what a person might, or might not, have anticipated when making an advance statement. It is certainly impossible to judge whether or not this would have affected the decision. The vague wording of this clause makes it far too easy for those who have their own reasons for opposing advance statements (and there are many such people, including doctors) to argue that the statement is not valid. One of the freedoms we must have, when taking an advance decision, is the freedom to take a risk. Many of those making advance statements would prefer to take the risk that they might die a little sooner than absolutely necessary, rather than risk the unwanted interventions of invasive surgery etc.

If the thinking behind the clause is that a completely new and successful treatment might have been developed between the making of the advance statement and its implementation, then we suggest that this exception to its observance should be stated in terms. Though this possibility is always quoted among the reasons for opposing advance statements, such a happening is highly unlikely outside fiction. Under the current wording, minor variations in established treatment that doctors may believe "worth a try", could well be used to thwart the well-considered intention of the person drawing up an advance statement. That is surely the opposite of the Bill's objective.

Opposition to the Bill

Opposition from so-called "pro-life" groups is likely to be carefully orchestrated and vigorous. Following "Who Decides", thousands of protest letters were engineered and may well have been the cause of delaying this necessary legislation for so long. Alert put out its web site "Stop the Kill Bill" before any bill had been drawn up. Such groups are well organised, passionate and usually succeed in punching beyond their weight.

Opposition seems rooted in the religious belief that life is sacred and must be preserved at all costs. Underlying this is a conviction that refusal of treatment is tantamount to suicide and therefore a sin. No one would wish to interfere with anyone adhering to their own beliefs, but they cannot be allowed to inflict them on the rest of us. It is our basic right to refuse treatment and this right must be protected, even if we are unable to speak up for ourselves at the crucial moment.

The pro-life literature concerning the Bill concentrates on withdrawing and withholding nutrition and hydration. It asserts that this will become commonplace and will turn caregivers into murderers. However, as things stand, it is considered ethical for doctors to take this course if they consider that no quality of life remains. Therefore it can hardly be considered less ethical if it is the advance choice of the patient concerned. It is not essential for an advance statement—or authority given to an attorney—to include this provision and it is quite likely that only a minority will do so.

August 2003

110. Memorandum from Professor Michael Gunn, Nottingham Law School, Nottingham Trent University (MIB 1192)

1. The current law is not sufficiently clear to be allowed to continue in full application for much longer. If only for this reason, the draft Mental Incapacity Bill is to be welcomed. In fact, it is to be welcomed for more than this as it achieves a sound balance of varying interests.

2. The Bill's provisions only apply where a person is not capable of making decisions for themselves. The presumption of capacity (clause 3) makes it clear that the starting position is that everyone is assumed to be capable of making decisions for themselves. Whilst it is not entirely clear from clause 3, it is to be assumed that the burden of establishing that someone is not so capable would lie upon the person asserting it. What is clear is that the standard of proof is the ordinary civil one, ie on a balance of probabilities (clause 3(2)). There is no good reason why the criminal burden of proof (beyond a reasonable doubt) should have been adopted.

3. Further, the Bill makes clear what is capacity by way of a definition (clause 1 and clause 2(1)) that applies the only possible approach which is the functional approach.

- (a) There is no global assessment of capacity, rather an assessment whether an individual can make the particular decision in question. It relies upon the ability to make the decision and focuses on understanding relevant information, ability to retain, and ability to use the information.
- (b) Although the origins of the requirement to retain information as a separate element are the common law, it is difficult to see why it should be a separate element as it is, in truth, a part of the ability to understand (the person who cannot retain information at all cannot understand it, since to understand requires it to be in the mind for the understanding process to take place). Clause 2(4) would not be necessary were the separation of retention from the ability to understand not to appear in clause 2(1).
- (c) The ability to understand is clearly a critical element. But so also is the ability to be able to use that information. A person cannot be regarded as capable if they have the capacity to understand but not the capacity to use that information to make a decision. This requires an ability to rationalise, but it does not require the decision to be a reasonable one (see also clause 2(2)), so it is a process requirement and not an outcome requirement.
- (d) Crucial to the success in practice of the definition will be determining what information must be understood and processed. The more information and the more complex that information, the more likely that a person will not be able to understand or use it. Clearly most people are capable of making most decisions (an important initial proposition) and so no approach to capacity must result in those people being regarded, in fact, as incapable. The fact that they will not have to be assessed is true, but nevertheless, were they to be tested, they must be able to satisfy someone that they are indeed capable. This means that the amount of information to be understood must be that which the ordinary decision-maker must also be able of understanding and using.
- (e) One real danger is that a person about whom capacity in question is required to go through tests which turn out to set a standard that most or many or some people presumed to be capable would not pass (but, to repeat myself, they are not required to pass the test as their capacity is never put to scrutiny).
- (f) This is why it is important to ensure that the amount of information to be understood and used is consistent with that which most decision-makers can handle for themselves (and possibly with some help). Much of this guidance would need to be placed in a well constructed Code of Practice that is supplemented by high quality training and education so that those involved in the delivery of care to vulnerable adults and those involved in assessing decision-making capacity have the right understanding and as much guidance as possible such that they make valid and reliable decision and use appropriate approaches with regard to their client group.

4. It is a significant step that the legislation mandates the requirement to facilitate the person in making their decision (clause 2(3)). This underpins the desire to ensure that people make their own decisions wherever possible. It should also underpin the requirement not to set too high standards for capacity. What will be required by "facilitation"? Some guidance will be needed at least in the Code of Practice. The sort of factors to take into account in addressing the issue will include relevance of cost, time and other resources, and a recognition of the fact that someone cannot necessarily be made capable. However, simplification of tasks and repetition of tasks are two approaches that, in many, cases will make a difference. Further, even if someone does not become capable of making the decision for themselves, they may nevertheless be more involved in the process (as to be taken into account when considering the best interests, see clause 4).

5. Where a person is not capable of making their own decision, the only viable approach is a best interests approach, unless a person has already made a relevant decision themselves.

- (a) The Bill allows an individual to make that decision and for it to be determinative through various approaches, not least the ability to grant someone a lasting power of attorney and the ability to make an advance decision to refuse treatment.
- (b) But also the definition of best interests emphasises that the individual's wishes and feelings etc (clause 4(2)(c)) are factors to which regard must be had. They are, therefore, not determinative, and cannot be.
- (c) Accepting that best interests is the only viable approach to making decisions where someone is not capable and has not legitimately made the decision (or created the means for making the decision) in advance, enables a careful assessment of the definition of best interest in clause 4. Whilst the legislation does not say so, it must be the case that there is only one course of action that is in the best interests of a particular individual. This is the point to which the courts have come in interpreting the common law jurisdiction to declare what is in the best interests of an incapable adult after the decision of the House of Lords in *Re F* [1990] 2 Appeal Cases 1.
- (d) Of course, clause 4 provides no definition, but rather indicates that to which regard must be had in deciding what is in a person's best interests. This is the approach of the Law Commission and has received broad agreement over the years. The reality is that, at the end of the day, a decision has to be made on behalf of someone who cannot make it for themselves, after determining that which is relevant. When that has been done the decision reached must be the selection of one from what may be a range of options that in the opinion of the decision-maker (and subject to challenge through the court) best serves the interests of the incapable adult in question.

6. The Law Commission, in developing the same broad structure as that in the current Bill, developed certain basic principles that underlay their proposals and underlie this legislation. They do not need to be re-stated on the face of the legislation, but it is important to be clear that they do underpin it and that the legislation does comply with those criteria. In its 1991 consultation paper, the Law Commission identified those principles as being: normalisation, the presumption of competence, the least restrictive alternative, providing safeguards without stigma, and achieving a balance; and the broad propriety of those principles was confirmed by the Law Commission in its 1995 Report. Further to these principles is the need to be at least compliant with the European Convention on Human Rights, particularly Articles 6(2) and 8, and some of these issues are raised below.

7. The Law Commission and the drafters of this draft Bill are keen to achieve an improved position for vulnerable adults who cannot make their own decision. Further, any approach must achieve practicability. It is no point introducing a system that, whilst theoretically perfect, has no practical reality.

- (a) The general authority to act reasonably (clause 6) endeavours to establish an approach that achieves the necessary practicability as it makes possible decision-making on a swift and principled basis that does not stretch budgets but whilst making sure that this does not apply in some circumstances (eg where there is a donee of a lasting power of attorney, etc), that some decisions cannot be made and that all decisions made through this approach are subject to the possibility of challenge. It is right to exclude very personal decisions, ie those decisions that really only someone deciding for themselves can make (see both clauses 7 and 26–29). More complex decisions will involve reference to the court, assuming that no other relevant decision-making structure is in place.
- (b) One problem to be addressed is that there is no need to go to court to trigger the jurisdiction of the general authority to act reasonably. It might be alleged that this is a breach of either Article 6(2) or Article 8 of the European Convention on Human Rights. In fact, the draft Bill does provide a right of access to the courts, as it is possible to challenge decisions, and someone could challenge on behalf of the incapable adult. The real issue is whether the right to challenge does sufficiently protect the incapable adult. Some situations arise where the only people involved are the incapable adult and the person exercising the general authority. In this case, how are the interests of the incapable adult protected, ie how might a case get to court and how can we be sure that challenges that ought to be issued are so issued? The first response is to recognise that this system will not prevent all bad decisions, but it should not be imagined that a court-triggered system would do better. In many cases, the likelihood of a case being taken to court to trigger an authority to act is as low as a challenge being issued. This is not to be defeatist, but to be a realist. No system can prevent all bad decisions. The question is whether a good system is introduced and whether a better and adequately practicable system is available. The advantages of the general authority to act reasonably are first that it is practicable. Many decisions need to be made and the cost of any court-based system will produce means to avoid it because it will be perceived as too expensive and bureaucratic to deal with the situation. This would mean more bad decisions not being challenged than under the proposed system. Further, why should all decisions go through a court? A cogent argument can be made that to do so would be a breach of the Article 8 right of the incapable person to have their private life protected. It is submitted that there is, in reality, insufficient protection produced by a court-triggered system to warrant every decision having to go through a court or to be initiated by a court (eg a court appointing a manager to make decisions, etc). What Article 8 requires is that proper protection be provided for vulnerable adults whilst not imposing unacceptable restrictions on their freedom. This was clearly stated to be the position in *X and Y v*

Netherlands, where the European Court decided that the balance was wrong as the vulnerable person had no right to initiate a police investigation by someone making a complaint on their behalf of sexual offences when they were incapable of doing so themselves. But the Court explicitly recognised the need to reach an appropriate balance between the freedom of sexual expression and the need to protect vulnerable adults—this is analogous to the present situation.

- (c) In conclusion, the proposed procedure provides an appropriate balance of the various ECHR rights. The proviso would be that the Code of Practice should endeavour to underpin the proper approach, means of challenge should be as simple and expeditious as possible, education and training of professionals and carers is vital, and education of the public to understand what are the limits of deciding on behalf of incapable adults (eg elderly and now incapable parents or other relatives).

8. What does not appear in the legislation but what was proposed by the Law Commission was a variety of means of dealing with some types of decision that it thought should not be determined by the general authority to act reasonably (eg a second opinion procedure in relation to some proposed treatments). Under the draft Mental Incapacity Bill, these will have to be dealt with either where there is a lasting power of attorney or through the Court of Protection. There were some significant advantages of the Law Commission scheme, particularly in terms of practicability and cost. The schema would enable certain treatments to be approved, without relying on the general authority to act reasonably, but without having to have recourse to a court decision. However, it may be that the demands of Articles 8 and 6(2) make a system of going through the Court a more appropriate approach for such treatments or other decisions. Requiring some decisions to be made by the court helps the argument propounded in note 7 above, as it demonstrates that considerable care has been taken in determining those decisions that can properly fall within the general authority to act reasonably (subject to a court challenge) and those that really need that authorisation in all cases.

9. Priority is given, over the general authority to act reasonably, for decisions made by a donee under a lasting power of attorney or a deputy appointed by the court (cl. 7(2)). This pays due respect to the principle of autonomy that underlies this proposed legislation. It can briefly be stated as being (a) a person makes those decisions that they are able to make; (b) where they cannot so make them at the time, priority is given to an advance decision to refuse treatment; (c) where they cannot so make them at the time, priority should subsequently be given to the person appointed by them to make those decisions; (d) where no such provisions exist, then decisions are made by reliance upon the general authority to act reasonably, except where the Court is involved and it may appoint a deputy to make such decisions. In principle, there seems in this approach to be due regard paid also to the protections provided for vulnerable people under Articles 8 and 6(2) of the ECHR, as mentioned also above.

10. Clearly, the ability to make a lasting power of attorney is a key approach in achieving a proper balance of the relevant interests. Crucial elements of the proposal to be welcomed are: (a) a clear statement as to the broad range of decisions that the donee will be able to make (cl 8(1)), with some clear exclusions including decisions that are too personal to be made by anyone else (cl 26), but also identifies certain decisions that can only be made if certain additional protections are available (see cl 10 in relation to the use of force to secure the doing of an act or a restriction on P's liberty; cl 11 in relation to gifts, see cl 11(2) for a sensible approach to those gifts that can be made); (b) a clear statement as to the way in which a lasting power of attorney can be made. Whilst concerns have been expressed about the need to register such documents, this must be an element of protection from improper decisions etc etc etc (c) a clear statement of the required qualities of the donee—clearly this cannot in legislation go very far, but no doubt either the Code of Practice or other guidance will raise matters that ought to be considered in relation to who to appoint (eg their age relative to the age of the donor; their fiscal capacity where finances are to be controlled; their abilities to respect others decision-making structures and approaches and to respect the need to make decisions in accordance with best interests, etc); (d) a clear statement of the circumstances in which a lasting power of attorney can be revoked, notably the donor, with capacity, revoking it (cl 11(2) and the incapacity of the donee causing revocation (cl 11(4) & (5)); (e) there is protection provided for the donee (necessary otherwise people may not agree so to act for fear of liability arising improperly); (f) and further protections through the role of the Public Guardian.

11. There must be a means of challenging various issues in court to satisfy Article 6(2), as is readily recognised by all those thinking about the ways in which decision may be made on behalf of people who are incapable of making them for themselves. It is important, therefore, that the court has the power to make the declarations as stated in cl 15 and so alter the understandable but awkward common law position post-*Re F*. In terms of the exercise of its discretion, the Bill retains the preference for the court to make a decision rather than to appoint a deputy (cl 16(4)(a)). This is readily understandable as a desire to limit decision-making on behalf of others and to provide a protection against abuse of the power by keeping limited the range of activities for deputies. This is supported by the desire to limit the scope and duration of deputies' powers whenever possible (cl 16(4)(b)). The areas for decision-making by the court and the potential powers of a deputy are inexhaustively listed in cls 17 & 18. The advantage of this approach is that it indicates the usual types of decisions that will need to be made and discourages moving into other permissible and potential areas unless there is a clear need so to do. The lists draw on existing case law in relation to both personal welfare matters and property and affairs and so reflect those decisions that in practice do need to be made.

12. Where a court has to appoint a deputy, it is important not only to be secure that the court's discretion will have been exercised appropriately (and is subject to appeal), but also that there is sound limiting of the discretion as to who to appoint, which appears to be achieved by cl 19. Further, the restrictions on the activities of a deputy in cl 20 similarly appear to be proper, notably the requirement that, even though properly appointed, a deputy should not make a decision where he knows or has reasonable grounds for believing that the donor now has capacity (cl 20(1)). This clearly underpins the legislation's commitment to respect for the principle of autonomy.

13. Much of the success of this legislation, as has already been noted, will depend upon the guidance provided in the Code of Practice. This Code will have a range of audiences with a range of needs. This includes health care providers. Some providers have regular contact with and experience of such vulnerable adults, such as learning disability provision and mental health provision; some providers may have fairly regular contact but not as much experience, such as accident and emergency; and some may have little contact or experience. Carers are an important audience. Some will have developed considerable expertise (especially the parents of people with learning disability), but others will have little experience or preparation (eg relatives of adults developing dementia, etc). Thus, the Code needs to address the needs of both professional and non-professional persons; experienced and non-experienced people, etc. But the Code alone will not ensure the delivery of this legislation in the manner that it deserves and needs so as to make life better for vulnerable adults, there is also a significant need for education and training. The needs of many professionals can be identified and thus education and training planned in advance. But it is less easy with some professionals and some carers, upon whom a dilemma may be thrust. Therefore, there needs to be general education about the need to know when a person cannot make their decisions and to whom to turn to for help. One of the most difficult issues, alluded to above, is the need to ensure that the procedures under the legislation are triggered when needed. Once triggered, there are adequate protections, but if the procedures of the Act are not triggered, there is no protection for a vulnerable adult, though there is not necessarily abuse.

October 2003

111. Memorandum from the Catholic Union of Great Britain (MIB 1193)

THE CATHOLIC UNION

2. The Catholic Union was founded in 1871 and is an independent lay organisation representing the voice of lay Catholics in public life and is not party political. Its President is currently a Labour peer and former Chairman of the Bar Council, Lord Brennan QC. It has representatives in the regions and is a consultative organisation of the Catholic Bishops' Conference of England and Wales.

3. The Union has a number of committees including the Joint Medico-Ethical Committee with the Guild of Catholic Doctors and their joint submission is already before the committee.

4. These submissions are supplementary to that submission.

SUMMARY OF CONCLUSIONS

5. A greater role for patient advocacy or consultation is a desirable and indeed laudable aim but that concept is fundamentally different from the concept of an attorney.

6. An attorney has *power* (within the scope granted) to *order* the withdrawal and withholding of treatment from the patient, *as if he were the patient himself*.

7. Lasting Attorneys (LPA) and Deputies (who are likely to be social workers) need not be medically qualified but will make medical decisions about somebody else's health *without having any clinical duty of care* even if they make a clinically negligent decision that harms the patient. The attorney and Deputy will thus have power without responsibility and will be clinically *unaccountable*. That is a serious *lacuna*.

8. Almost the same difficulties lie with advance decisions. The current law provides adequate safeguards for advance decision making which will be cast aside by MiB. See the case of *Re: AK*.

9. The best interests criteria in s.4 of the Bill are non-clinical and will clash with clinical criteria. Despite s.21(3)(b) and s.31, an AD or LPA will be able to authorise withdrawal of treatment (which may include food and fluids) because s.4 defines such decisions as in the patient's best interests. The proposed safeguards will therefore not protect the patient from clinical harm or neglect and s.21(3)(b) and s.31 are therefore misleading provisions. They are unlikely to prevent breaches of Articles 2 and 3 of the Human Rights Convention. Recent case law underscores this point as does the Opinion of leading public lawyer Richard Gordon QC.

10. Both an AD and an LPA could *require* a doctor to withhold treatment (even sustenance by tube) even if the doctor believes he can restore the patient to health. A doctor could thus be disciplined or even prosecuted for *not* withdrawing clinical treatment that the patient needs in order to be restored to health. A doctor might even find himself disciplined or prosecuted for *not* dehydrating his patient. This is an impossible position in which to put doctors and breaches the fundamental medico-legal principle that doctors should first do no harm (*primum non nocere*).

11. Moreover, LPAs are likely to be relatives who might well stand to benefit (eg through a will) from the patient's death. The Florida cases of *Schiavo* and *Night* are examples of such potential abuses and the current case of *Nockels* in Norfolk may well be another.

12. On the other hand statutory consultees or patient advocates have none of these dangers. Healthcare workers could be required by law to consult them but will not be bound by clinically negligent decisions. Such a schema would, in my view, meet most of the requirements of those seeking a change in the law but without the dangers I have adumbrated herein.

13. A more detailed analysis follows in the Annex hereto.

THE PROVISION OF BASIC CARE AND THE LEGAL BACKGROUND

1. The legal background must be considered when interpreting the various clauses of the MIB. In particular, the decisions in a few leading cases have tended to blur the distinction between medical treatment and the provision of "basic care" eg hygiene, pain relief and, particularly, food and fluids whether oral or by tube.

2. Most previous consultation papers and draft bills have made at least a requirement for the provision of "basic care". That is apparently absent from the present draft. Thus it is not necessarily clear if such basic care—as a bare minimum—is obligatory. Most people will agree that all patients should be kept clean and, so far as possible, pain free. But the MIB makes no apparently obligatory provision for such "basic care".

3. Furthermore, the current position in case law as regards the provision of tube feeding is far from unambiguous. It appears that such may be regarded in some cases as "medical treatment" and thus could be withdrawn if a group of doctors felt it was not in a patient's best interests. If food and fluids, however delivered, are withdrawn from a patient who is not dying, the patient will *certainly* die from such withdrawal, usually by dehydrating to death.

4. The current state of case law, where relevant, is reviewed below¹¹⁷.

¹¹⁷ *The Bland case*: In the leading case of *Airedale NHS Trust v Bland* [1993] AC 789, HL, the House of Lords were called upon to decide what should happen to a young man who had suffered severe brain damage after being crushed watching a football match and was rendered into the condition known as PVS, the Permanent or Persistent Vegetative State (which is not to say that he had become like a vegetable—a common misnomer). The court decided, among other things, that a patient in PVS could lawfully have his or her feeding tubes removed so that the patient then died of dehydration. The court said that, in the case of PVS patients, such feeding was medical "treatment" and could be withdrawn.

That distinction will be highly relevant in the case of Advance Decisions (AD) and Lasting Powers of Attorney (LPA) as will be seen because both can contain powers to refuse treatment. If treatment includes food and fluids delivered by tube then the donee of such powers or the AD itself could require medical staff to dehydrate a patient to death, a clear and unambiguous example not only of passive intentional killing (or euthanasia) but one that a doctor could be ordered to undertake on pain of very serious legal sanction.

Re M and R H and Pretty: Bland has been declared compatible with the Human Rights Act in the cases of *Re H and Re M* [2001] 1 All ER 801, by the President of the Family Division, Dame Elizabeth Butler-Sloss on the rather unusual grounds that since the withdrawal of the food and fluids delivered by tube was a withdrawal of "treatment", such treatment can be withdrawn if a body of doctors expert in that field would have agreed it was appropriate. This seems to run counter to the principles set out in *R v Gibbins & Proctor* 13 Crim App Rep (1919) 134, (and other similar cases *R v Cox* (1992) 12 BMLR 38; *R v Bodkin-Adams* [1957] CLR 365 (CCC)) and, moreover, it is by no means clear that dehydrating PVS patients to death is a distress-free exercise so as to take the matter outside the range of "degrading and inhuman treatment" under Article 3 of the Convention. The decision may well be re-visited at a higher judicial level, particularly in the light of the decision in the case of *R (Pretty) v DPP (SSHDI intervening)* [2001] 3 WLR 1589; [2002] 1 FLR 268, in which the application of a person seeking help to commit suicide with legal impunity was refused.

The current law on Advance Decisions: It has been said by some that such are already binding in law. That is highly misleading and is an incomplete statement of the law as it now stands in the light of the leading case of *Re: AK* [2001] 1 FLR 129. It would be most helpful if the judgement of Mr Justice Hughes could be quoted in full as it offers very practical and explicit advice to doctors beyond which it is unnecessary to go. This is what the judge said at [2001] 1 FLR 134E-G:

"It is . . . clearly the law that the doctors are not entitled so to act if it is known that the patient, provided he was of sound mind and full capacity, has let it be known that he does not consent and that such treatment is against his wishes. To this extent an advance indication of the wishes of a patient of full capacity and sound mind are effective. Care will of course have to be taken to ensure that such anticipatory declarations of wishes still represent the wishes of the patient. Care must be taken to investigate how long ago the expression of wishes was made. Care must be taken to investigate with what knowledge the expression of wishes was made. All the circumstances in which the expression of wishes was given will of course have to be investigated. In the present case the expression of AK's decision are recent and made not on any hypothetical basis but in the fullest possible knowledge of impending reality."

LASTING POWERS OF ATTORNEY (SS.8–13)

5. No Duty of Care owed by Lasting Attorneys

6. Provided an attorney acts within his given powers he cannot be sued, even if his decisions were clinically bad ones. Whereas doctors have a duty of care and can be sued for clinical negligence, Lasting Attorneys cannot—they have no duty of care. The damage may cause financial loss to the donor. If the attorney is empowered to make medical decisions then the damage may be lasting or permanent physical damage or even death to the patient. It is important to realise that provided the attorney acts within his powers under the MIB, he cannot be sued even if he makes clinically unsound decisions.

7. More importantly, the powers granted under an LPA can, if so framed, enable an attorney to *require* a doctor to withdraw or withhold treatment from the patient, because the attorney *stands in the shoes of* the patient—and the patient has an absolute right to refuse treatment when it is offered.

8. Intentional termination of life—a new prospect under MIB

9. Given that the law recognises (see above) that in some circumstances even *food and fluids* by tube can be withdrawn (because they can be considered treatment in some circumstances) then a Lasting Attorney will have the power to *order* a doctor to withdraw sustenance from a patient. If sustenance is withdrawn then a patient *inevitably* dies. Thus it will be possible for Lasting Attorneys to have power effectively to *order* a doctor to bring about a patient's death.

10. Thus doctors could be *required* to terminate a patient's life intentionally. If the doctor does not follow the directive of the Lasting Attorney to withdraw the "treatment" (or even sustenance by tube) then that doctor may not only be liable in civil law but may be liable for the *criminal* offence of assault. If convicted he could be struck off the register.

11. Thus the MIB introduces a potentially odd situation whereby a doctor is *criminally* liable for assault if he does *not* bring about the termination of the patient's life deliberately and intentionally by withdrawing sustenance. This brings the law into immediate and serious disrepute by undermining the very law of homicide. To charge a doctor with assault for *not* terminating his patient's life is hardly reasonable, just or wise. Yet this could happen under the MIB.

12. One must also consider the effect upon the morale and ethical standards of the Health Service if doctors can be disciplined or even prosecuted for refusing to terminate a patient's life by withdrawing sustenance. The principle of "First Do No Harm" (*Primum Non Nocere*) is compromised and the Hippocratic tradition of medicine undermined¹¹⁸. If the doctor is obliged to withdraw sustenance by tube from a patient on the direction of a Lasting Attorney then a fundamental principle of medical ethical principles will have been compromised. Moreover, no doctor will be able to avoid the directive of the Lasting Attorney since the sanction for disobeying the LPA will be a very serious one, and even potentially criminal.

13. The activities of negligent or unscrupulous doctors will be given a plausible cover which might, in fact, mask a deliberate intention to end life.

14. Further, one must consider the extent to which ending a patient's life by dehydration is a cruel method of terminating life. The body dries up, in effect. The eye sockets dry up, the skin becomes flakey and dry, the tongue dries up and turns black, and the brain sends distress signals all over the body: it is an unpleasant way to die and very unpleasant for relatives to observe. Relatives will ask why the patient cannot be given a lethal injection and, indeed, some have already said that such a death is cruel and that a lethal injection should indeed be administered. That, plainly, is a call for direct, involuntary, intentional homicide.

15. Other potential abuses made possible

16. Consider further the situation where a Lasting Attorney is also a beneficiary under the patient's will and stands to gain financially by the patient's death. The scope for abuse is immediately obvious. And in many cases the attorney is *likely* to be a close relative who might also benefit from the will.

17. Lest this scenario be thought unlikely an example should assist.

18. In a Florida circuit court an order¹¹⁹ was made withdrawing and withholding food and fluids from Marjorie E. Nighbert at the behest of her brother, Maynard Nighbert who held a durable (ie Lasting) power of Attorney. Miss Nighbert had suffered a stroke but it was said she had made indications of wishing to be fed. The court appointed a lawyer to investigate her capacity but it was concluded that she did not have capacity to withdraw the LPA and that her brother's decision to *require* the doctors to refuse food and fluids *must* be upheld.

19. Mrs Nighbert died not long thereafter from lack of food and fluids. Nurses said that she was still making signs requesting to be fed. It is thought that analgesic pain relief was administered but that is thought to be insufficient because dehydration acts upon the osmo-receptors in the brain which cause overall distress to the person and not just in the pain centres. Analgesics affect the pain centres not the osmo-receptors. Mrs Nighbert may well, therefore, have died in great distress.

¹¹⁸ At present doctors are forbidden to participate in judicial executions because of the "No Harm" principle and because their vocation is to heal and alleviate pain. The most a doctor can do is testify that the condemned is certifiably dead.

¹¹⁹ Case no. 95-4-PSA in the First Circuit Court of Okaloosa County (Probate Division), Circuit Judge Jere Tolton presiding.

20. This is but one example of the many ways in which an LPA can have the effect of *undermining* rather than enhancing a patient's autonomy.

21. Moreover the patient may not die but may, rather, suffer serious long-term damage instead.

22. Consider this example. A young man of 18 who is run over in a motor accident may have suffered a fractured femur but also been rendered unconscious with suspected brain damage. He may have an LPA which provides for the withdrawal of treatment in the event of mental incapacity. In that case the Lasting Attorney may require the withdrawal of treatment on the grounds that the patient would not want to survive in a brain damaged state. The doctor would then be obliged to withhold treatment even though he could readily treat the fractured femur.

23. Now suppose that the patient after some months regains consciousness and, in fact, suffers little or no brain damage, despite the prognosis. The fractured femur will not heal itself and by the time some months have passed it may well be too late to heal it. The patient will thus be crippled for life—at the age of 18—and he will have no remedy against the Lasting Attorney (acting within the scope of the LPA), because the attorney has no duty of care and cannot be sued for clinical negligence, nor against the doctor who will have had to follow the Lasting Attorney's demand to withhold treatment and thus is not liable.

24. Thus death may not ensue but, rather, lasting damage that could cripple a healthy person's life.

25. The same scenario could apply to an elderly person suffering from, eg stroke. A withholding of treatment may not necessarily result in the patient's death. They may simply deteriorate and live a miserable existence for a much longer period simply because, under the power of the LPA, the Lasting Attorney required the doctor to withhold treatment. This, indeed, appears to be what is happening in the *Schiavo* case in Florida, USA¹²⁰.

26. These are but a few of the potential hazards of introducing legally binding powers such as that of a Lasting Power of Attorney.

27. *Consultee or Advocate is preferable to Power of Attorney*

28. The desire for relatives, loved ones and friends to be consulted does *not* require anything so sweeping and far-reaching as a power of attorney. A legal requirement for them to be consulted as either statutory consultees or advocates is all that is required. Then if the doctor acts without consulting them he can expect to be open to a civil suit and/or a complaint to his professional body and the matter would be serious.

29. The unwelcome scenario of a doctor being *required* to act against his clinical judgement—or worse to terminate his patient's life—would, however, be avoided. Most patients simply wish to be sure that their appointed advocate or consultee is consulted so that they are kept fully in the picture by the medical staff and can see that the patient is being well cared for. That is what most people desire and a consultee or advocate can achieve that.

30. The establishment of a statutory power of attorney goes too far and is attended by very considerable risks not only to the patient but to the medical profession and to the general public as a whole. This is clear from ss 8, 10, 12 and 13 and the powers of the court set out in ss 21 and 22 do not obviate the problems outlined above since the court will be concerned to determine whether or not the LPA is valid, not whether the attorney's decision is clinically negligent. If the power is valid and not obtained by fraud or undue pressure, the court's interest lapses save in one circumstance.

31. That is outlined at s 21(3)(b), namely where the court is satisfied that the Lasting Attorney has behaved, is behaving or is proposing to behave in a manner incompatible with the patient's best interests. It can be seen below that there are considerable problems with the "best interests" criteria in MIB but the chief problem is that it is clear that, under the current state of the law (see above) and the wording of s 4 of MIB, it is not necessarily contrary to the patient's "best interests", as qualified by s 4, to suffer loss of life by the withdrawing or withholding of necessary treatment (or even sustenance by tube).

32. Given the fact that many people, including doctors, will not be aware of the current state of the law, this aspect of the MIB may well not be fully appreciated. Once it is clear that "best interests" may not necessarily rule out the withdrawing or withholding of necessary treatment (or even sustenance by tube) from patients, then the dangers can be readily seen. Since the "best interests" criteria have been widened by s 4 to accommodate the concepts of LPA and AD it can be seen that the introduction of these concepts will permit the new "best interests" criteria to overrule *clinical* best interests so that a doctor can be *required* by the Lasting Attorney (and an AD) to do what his clinical judgement rejects—including even withdrawing and withholding sustenance by tube so that the patient then dies of dehydration. Thus it may not necessarily be against the patient's "best interests" to terminate his or her life by removing necessary treatment (or even sustenance by tube).

33. Moreover, s 21(3)(b) does not provide anything like the kind of protection that, at first blush, it appears to provide. Indeed, this paragraph is likely to serve to confuse rather than allay fears. It will give a deceptive impression of protection that is simply not there.

¹²⁰ Case no. 8:03-cv-1860-T-26TTGW in the Tampa Division of the Middle District Court of Florida, following an order by District Judge Richard Lazzara on 30 August 2003.

34. Likewise s 31, which stipulates that it will be an offence for a person to ill-treat or wilfully neglect the person over whom they have power of attorney or care, will not of itself necessarily prevent decisions to remove treatment (or even sustenance by tube). The LPA (or AD) may require such and yet will still have to be followed. Thus, again, the wider and more subjective “best interests” criteria in s 4, which goes beyond clinical best interests and includes decisions under an LPA or an AD so that they are *by definition* within “best interests”, may permit withdrawing and withholding of necessary treatment (or even sustenance by tube) as being treatment which is outside the patient’s “best interests”.

35. Thus, again, the scope of s 31 is likely to cause untenable and misleading reassurance—a reassurance which is not justified.

36. Accordingly, the concept of Lasting Attorney would better be replaced with a concept of statutory consultee and/or advocate.

COURT-APPOINTED DEPUTIES (SS. 14–20)

37. Of greater concern still is the power of the court simply to appoint a “Deputy” to make decisions to withdraw and withhold sustenance and treatment even though there is *no* LPA. Under s.17(1)(d) and (e) of MIB the court-appointed “Deputy” will have power to make “personal welfare” decisions including:

- “giving or refusing consent to the carrying out or continuation of a treatment by a person providing health care for P.”

38. Thus all the problems arising under LPAs are reproduced in the appointment of a “Deputy” *but* the “Deputy” will *not even* be appointed by the patient himself or herself but rather by a public body. Moreover, it is highly likely that such an appointee will be some official such as the chief Social Worker for the area concerned. Thus the chief Social Worker for the area is likely to be making decisions about the provision of treatment (or even sustenance by tube) to the patient and thus perhaps making a decision about whether that patient should continue to live or not, even though that social worker is not medically qualified and has no medical duty of care. That is clearly a matter for considerable concern.

ADVANCE DECISIONS (SS.23–25)

39. The concept of Advance Decisions is similar to the LPA save that instead of giving to an attorney the power to order withdrawing or withholding treatment, a legally binding decision or instrument is made by the patient themselves in advance of becoming incapacitated.

40. The same problems arise under these as with LPAs. The patient’s autonomy can actually be undermined by him or her being unable to revoke an AD due to lack of capacity whilst nevertheless wishing to be treated or receive sustenance.

41. For example, a patient may be “incapacitated” within the meaning of the MIB but still be able to hear or comprehend what is happening. A patient in certain types of condition can still hear and understand but not communicate their wishes to medical staff or others. The patient’s wishes may be overridden by their *own* AD which they are unable to revoke due to being unable to communicate. In such a situation the patient’s autonomy is exploded not enhanced if treatment is refused when the patient, in fact, desires it but cannot communicate that desire.

42. The obligations of the medical staff will be the same as with LPAs in the sense that any refusal by a doctor to withdraw and withhold treatment including, in some cases, sustenance by tube where the AD stipulates such withdrawal or withholding, will put the medical staff at risk of civil and *criminal* sanction.

43. The same potential compromise of the law of homicide is thus risked by the legally binding AD.

44. Moreover, since there is nothing in the MIB which requires an AD to be in writing it seems that an oral AD may be sufficient. The scope for abuse in such a situation is correspondingly augmented to a considerable degree, since evidential difficulties are likely to arise along with competing assertions about the existence of an oral AD.

45. A person threatening suicide may be held to have made an AD if they state they do not want treatment even if the suicide threat is no more than a cry for help. Some suicides can appear very calm and rational but nevertheless still only intend no more than a cry for help. An AD may mean that they are not treated and simply die or suffer long-term harm.

46. Unlike the provisions for LPAs, there is not even an *attempt* to provide some sort of exclusion by the court on the basis that the AD is not in the patient’s “best interests”. It may simply be *assumed* that a patient’s best interests are served by his AD even if it requires the doctor to withdraw life-saving treatment, or even sustenance by tube, provided the purely technical formalities of the AD are met.

47. This demonstrates clearly that the “best interests” criteria in s 4 do not rule out the termination of life-saving treatment, the withdrawing or withholding of necessary treatment including probably even sustenance by tube, provided that is what the AD stipulates.

48. Once again, then, doctors will be in clear danger of being *required* to act contrary to their clinical judgment and even to be the immediate agent of the patient's likely death by withdrawing or withholding treatment and, where sustenance by tube is withdrawn or withheld, the patients' *certain* death¹²¹.

49. Moreover, by s 25(3), a person who withholds or withdraws such treatment will not be liable even if there is *no* AD, provided he or she reasonably *believes* that there was one. That is a very wide "let out" clause and may result in withdrawal of treatment in disturbing situations, and even situations of unscrupulous conduct.

50. Thus, once again, the prospect of a criminal charge of assault arises for a failure to terminate the patient's life. This once again turns the law of homicide on its head and compromises a fundamental principle of universal medical ethics. It cannot be right for a patient's AD to *require* a doctor to terminate a patient's life by actively withholding sustenance however delivered. That is not to "let nature take its course" but rather it is to cause a patient to die of thirst. No doctor should be compelled to do such.

CAPACITY (ss.1–3)

51. It has been suggested that there is no settled law in relation to the definition of capacity. That is simply wrong as the President of the Family Division, Dame Elizabeth Butler-Sloss, has made clear in the case of *Re: B*¹²². She said that:

— "The general law on mental capacity is, in my judgment, clear and easily to be understood by lawyers . . . In a series of cases during the 1990s the House of Lords and the Court of Appeal restated the long-established principles which govern the law on mental capacity of adults and provided some guidelines in complex medical situations".

52. It is not necessary, therefore, to re-define capacity as MIB seeks to do.

53. Moreover, the definition in MIB has a number of flaws in the context of the remainder of the Bill. For instance, what constitutes "impairment of or a disturbance of the functioning of the mind or brain"?

54. It is very important to be clear because under the remainder of the provisions of MIB there may be decisions of life and death and any uncertainty about the limits of the definitions of incapacity may have potentially terminal consequences.

55. For the same reason it is potentially harmful to include within the definition a merely *temporary* impairment or disturbance. A patient may be in a position to regain capacity and may be unable to make a decision by reason merely of a temporary unconsciousness. If treatment were to be withdrawn by order of a Lasting Attorney that might pre-empt a decision that could be made by the patient upon his or her returning to capacity. But the patient may be dead before then. That is plainly a very serious *lacuna* in the definition of capacity.

56. For the present approach of case law to capacity see, *inter alia*, *Re: C* and *Re: T*¹²³.

57. A case law approach is to be preferred rather than the blanket statutory approach to capacity that is suggested in MIB.

BEST INTERESTS (s. 4)

58. The attempt by previous draft bills, Green papers and consultation papers to redraw "best interests" criteria in a non-clinical manner has been a continuing source of difficulty and controversy.

59. There is an intrinsic contradiction contained within such a definition. Medical practitioners are primarily concerned with determining what is in a patient's *clinical* best interests. They are hardly in a position to determine what is in a patient's non-clinical best interests since that is a matter for the patient's own autonomy. The patient's autonomy to determine matters of a non-clinical nature cannot logically be alienated to a third party, whether by statute or by LPA.

60. Clinical best interests do not necessarily coincide with patient wishes. Indeed, a patient may want what is not clinically indicated or refuse what is medically necessary. The question of patient autonomy in decision-making must not be confused with medical opinions as to the clinical best interests of the patient which are a matter of professional judgement. A doctor is not empowered to advise upon non-clinical best interests and it cannot be right to *require* him or her so to do.

¹²¹ The concept of an AD appears to have been first put before Parliament in 1993 in the Medical Treatment (Advance Directives) Bill [HL Bill 73, 1993], by a peer on behalf of the Voluntary Euthanasia Society. This is perhaps unsurprising because it is a legal device for *compelling* doctors to act in a manner that will terminate the life of a patient intentionally, thus forcing the doctor to act contrary to the fundamental principle of medical ethics to do no harm (*Primum Non Nocere*) which has always been one of the primary objections to euthanasia—voluntary or otherwise. It is not voluntary for the doctor faced with a legally binding AD. Thus legally binding ADs could, for the first time, require a doctor to terminate a life and the doctor's failure so to do may amount to a criminal offence of assault. This will be so if "treatment" is to include sustenance by tube. Removal of feeding tubes from a patient who is not dying will ensure that the patient dies *directly* as a result of that removal of tubes. And that removal will have to be carried out by a doctor or a nurse.

¹²² [2002] 1 FLR 1090 at 1095.

¹²³ [1994] 1 WLR 290, *per* Thorpe J; [1993] Fam 95.

61. S 4 of MIB includes a raft of criteria that are not objective and clinical but are vague and subjective. It makes no reference to the criteria in *F v West Berkshire HA (Re: F)*¹²⁴ which sets out an objective framework for clinical best interests which is easily understood by doctors, the courts and the public.

62. In matters of life and death it is most unwise to obfuscate the criteria by which doctors must act.

63. In addition there is a substantial "let out" clause in s 4(4) in that a carer need only have a "reasonable belief" that they act in a patient's best interests. Since the outcome might be the death of the patient that is simply not sufficient and removes existing protection that incapacitated patients have in law.

THE GENERAL AUTHORITY (S. 6–7)

64. There is simply no requirement for a "general authority" since such already exists at common law as is clear from, *inter alia*, the case of *Re: F*¹²⁵.

65. Moreover, s 7(1)(b) mentions "risk of significant harm to P" but does not make it clear whether or not that means death in all circumstances. That is important since it is sometimes considered that death is not "significant harm" for certain types of patients—a subjective concept which has obvious potential for undermining a patient's autonomy and a doctor's ethical obligations.

THE HUMAN RIGHTS ACT 1998 AND THE EUROPEAN CONVENTION ON HUMAN RIGHTS

66. In the light of the above, it is my view that the MIB may not be fully compliant with the Convention, particularly Articles 2 and 3. The recent decision in the Diane Pretty case reinforces my view¹²⁶.

67. In particular I consider that:

- (a) MIB appears to be incompatible with Article 2 of the Convention because it appears to fall foul of the state's obligation to provide protection of the right to life which right is a positive obligation on the part of Member states.
- (b) MIB does not provide the necessary framework within the context of Article 6 to protect the right to a fair hearing in protection of the individual citizen's right to life under Article 2 and right to be free from inhuman and degrading treatment under Article 3. Dehydration to death must surely amount to inhuman treatment if not more.

CONCLUSION

68. I believe that the concepts of LPA and AD contain flaws of a fundamental nature that not only fail to answer and address the problem of autonomy and protection but, indeed, undermine both.

69. I believe that the better course for the assurance of proper consultation of relatives, loved ones and friends in the care and management of patients with mental incapacity is a system of statutory consultees and/or patient advocates.

70. Such a system would meet the desires of most patients and would, I believe, obviate most of the situations that have been adumbrated by representative organisations seeking to protect and enhance the autonomy of patients and the protection of the vulnerable incapacitated patient.

October 2003

112. Memorandum from the Islamic Medical Association UK (MIB 352)

I am writing to you to express my deep concern and objection to the new mental incapacity bill in context of the potential of withdrawal of food, fluids and necessary treatment to terminally ill/mentally incapacitated patients.

Islam like other monotheistic faiths upholds the sanctity and sacredness of life, so much so that an analogy of any individual terminating an individual's life is given in the Quran (chapter 5: verse 32); it is likened to the "slaying of the whole of mankind and on the contrary anyone saving a life, it is as if he has saved the life of all of mankind."

¹²⁴ [1990] 2 AC 1.

¹²⁵ *Ibid.*

¹²⁶ *R (Pretty) v DPP et al* [2001] 3 WLR 1598.

We have a responsibility and a duty to protect the most vulnerable in society as healthcare professionals and to place a clear and defining line between treating and harming our patients. One area where this can truly be exemplified is in the last hours, days or months of any terminally ill/mentally-incapacitated individual. Why deny their basic human rights; the simplicities in life such as food and drink when they are at their most vulnerable, possibly unaware or unconscious.

Many individuals cite “to die with dignity” is a basic human right and I would agree, to die with dignity means as medical healthcare professionals to provide necessary nutrients, fluids, medicines, analgesia and counselling/company to make an individual comfortable during their remaining years.

The introduction of any legislation allowing the withdrawal of food/fluid from any patient or to neglect life saving treatment is euthanasia by omission and a crime against the sanctity of life. The potential for abuse of this type of legislation by all members of society for personal, social or political gain is too of grave concern. This has only been recently emphasised by the “Shipman” enquiry where advantage of the more vulnerable groups of society lead sadly to numerous deaths over five decades.

Hence, I urge you on behalf of the members of the Islamic Medical Association (IMA) to reject the introduction of the mental incapacity bill and return basic human rights to all in society at a time where each and every one of us will be at our most vulnerable.

August 2003

113. Memorandum from the Royal College of Nursing (MIB 924)

The RCN welcomes the, long-awaited, publication of this draft Bill and the opportunity to comment on it. The RCN has been lobbying for some considerable time, in collaboration with other organisations, for legislation to protect vulnerable people.

The issues of incapacity are wide-ranging and cut across the whole spectrum of care and are particularly important in the fields of learning disability, mental health, older people and children’s nursing.

In general the RCN believes that the draft Bill clarifies a number of legal uncertainties and introduces valuable new decision making mechanisms to allow healthcare decisions, and those related to social needs and financial matters, to be made on behalf of people who lack the capacity to make such decisions. Furthermore, the RCN is pleased to see the inclusion of carers issues, and their rights included in the proposed legislation.

The RCN believes that this legislation needs to address comprehensively the issues of fluctuating capacity, restrictions on the liberty of individuals and the provision of adequate and robust safeguards for people who lack capacity—particularly those people referred to as “Bournewood patients”. Furthermore, the RCN would wish to see synergy between the proposed new mental health legislation, the incapacity legislation and their respective codes of practice.

The RCN welcomes the inclusion of “advance refusals” but believes that the proposed legislation would be strengthened if attention to “advanced directives”, or statements, were included within it. This issue, arguably, provides an example of the need for consistency within the proposed mental health and incapacity legislation, and within their respective codes of practice.

The RCN suggests that references to consent should be amended, and strengthened, by using the term “informed” consent.

The RCN wishes to see a fully funded implementation plan, and clear guidance, to accompany this legislation, when it is enacted, to ensure that nurses, and others, are properly prepared for the new roles that they will be required to fulfil.

The RCN welcomes this important proposed legislation and the principles set out within it, but believes that it would be enhanced by attention to these issues that RCN members have raised.

September 2003

114. Memorandum from Mr Ian Murray (MIB 925)

1. INTRODUCTION

1.1 I write with experience of having participated in the debate that took place in Scotland during the passage of the Adults with Incapacity (Scotland) Act 2000 (AWIA).

1.2 While acknowledging that the Draft Mental Incapacity Bill (MIB) does not apply in Scotland, where the law on these matters is governed by the AWIA, and I am currently resident in Scotland, it is possible that I may reside in another part of the UK at a later date and so be affected by the provisions in the MIB. On this basis I hope that the committee will take due cognisance of any submissions made from people in Scotland despite the fact that the bill will not affect those resident here.

1.3 The scope of the draft bill is very wide covering both financial and welfare matters. While the AWIA, dealt principally with financial matters the fact that there was a separate section on medical matters was I believe more helpful than the current situation with the MIB. Even within the area of welfare there is a wide range of issues covering simple every day affairs to matters literally of life and death. Legislation covering all these aspects of a person's incapacity in one parliamentary bill needs to be very carefully framed and in my opinion this has not been achieved in the draft bill. I think this applies in particular to Section 6 of the draft bill, The general authority.

2. AREAS OF CONCERN

2.1 All of the areas that are raised below are with reference to medical matters and are concerned primarily with end of life issues. While there may be no problem with the framing of the bill relative to day to day welfare matters there are I believe a number of concerns in applying this to end of life issues. These are contained in the following sections.

- Best Interests
- General Authority
- Lasting Powers of Attorney
- Advance decisions to refuse treatment

3. BEST INTERESTS—SECTION 4

Any decision made or action taken “in the person's best interests” is a judgement. When used in reference to medical treatment it is usually understood as a clinical judgement. The danger in the bill as drafted is that unlike the AWIA there is no specific section covering medical treatment. Section 4(2) of the MIB refers only to the past and present wishes and feelings of the person who lacks the capacity to speak for his or her self. The interpretation of “best interests” has been further confused by the statement of Lord Mustill in his judgement on the case of Tony Bland stating that because of his condition (PVS) Tony Bland had no best interests. Indeed it could be interpreted, from the statement “The concept of acting in the best interests of a person who lacks capacity already exists in common law” in the Overview of Bill published by the Department for Constitutional Affairs, that Lord Mustill's judgement was being put into statute law through this bill.

4. THE GENERAL AUTHORITY—SECTION 6

It is very noticeable, comparing the MIB with the AWIA, that the general authority in this draft bill is granted to anyone, whereas in the AWIA the general authority is particular to Part 5 of the Act Medical Treatment and is granted under section 47 to the medical practitioner primarily responsible for the medical treatment. If there is seen to be a need, to clarify the common law, for a general authority, there surely is a greater need to set out in more detail a general authority to enable doctors to treat in circumstances that currently may be seen to be problematic. The model of the AWIA could be used in this regard.

5. LASTING POWERS OF ATTORNEY—SECTION 8

There will be some, including some doctors, who see a danger in giving to those who have no medical training powers to instruct a medical practitioner to withhold or withdraw life sustaining treatment. There will be others, in particular life long carers, who feel that they know their loved ones better than any doctor and know what is best for the person in their care. Indeed their concerns may well be about every day matters rather than end of life issues. Those in the first category will have grave concerns, those in the second will welcome this part of the bill. Regardless of who exercises this power the most important aspect is that there should be sufficient protection in the bill for the donor (“P”). This was a real battleground in the debate on the AWIA. The end result was the insertion of a complaints procedure where there was disagreement

between the welfare attorney and the medical practitioner as to whether or not medical treatment should be withheld. This requires the medical practitioner to seek a second medical opinion and also makes provision for access to the courts if there is still disagreement after this procedure has been exhausted. A simpler clause outlawing the withholding or withdrawing treatment with the intention of causing death may have satisfied both camps. The provision in the MIB to use the Court of Protection as the ultimate authority over all areas of decision making for those who lack capacity will satisfy neither carers nor those who remain convinced that the case law judgement in the Tony Bland case is now being embedded in statute law.

6. ADVANCE DECISIONS TO REFUSE TREATMENT

6.1 It would appear from the current wording of the draft bill that advance decisions do not require to be in writing. While advance decisions can be helpful in advising a doctor whether to treat or not, they can be very dangerous if they become legally binding on doctors. Advance decisions that are merely verbal would be extremely dangerous. Clause 24 is intended no doubt to answer many of the arguments against making advance decisions legally binding on doctors. However it does not answer the most powerful argument that one's expectations of what is an acceptable quality of life often change the older one becomes. A statement made in one's 40s or 50s should not be binding 20 years later when perhaps one will lack capacity and be unable to withdraw it.

6.2 The introduction of advance decisions into statute law through The Mental Health (Scotland) Act 2003 was I believe a first in the UK; they are however only advisory. During the progress of this bill in the Scottish Parliament the committee took evidence from Helen Garner from the University of Glasgow, and David Cunningham Owens, Professor of Clinical Psychiatry, University of Edinburgh, who expressed grave concerns over advance decisions. A copy of the official report of the Health and Community Care Committee of the Scottish Parliament to which they gave evidence is attached to this submission as annex 1¹²⁷. Their evidence is on pages 44 to 53. Professor Owens was most particularly concerned when during the final stages of the debate an amendment to make advance decisions legally binding on doctors was put forward. In the event the amendment was defeated.

August 2003

115. Memorandum from Solicitors for the Elderly (MIB 930)

1. Solicitors for the Elderly (SFE) is a national organisation led by solicitors who are committed to providing and promoting a comprehensive range of high quality legal services for older people, their family and carers. We have in excess of 400 members. SFE welcomes, in principle, legislation in the area of mental incapacity. Such legislation would provide legal clarity generally in the area of decision making on behalf of adults (often the elderly) who lack capacity, empower those who have limited capacity to decide as much as they can for themselves, protect the vulnerable from abuse, encourage clients to consider seriously whom they wish to take decisions on their behalf in the event of incapacity and restructure the Court system both in relation to the Court of Protection and the new Public Guardian which is hoped will solve some of the existing problems which SFE's members, as practitioners working with the present Court of Protection and PGO, encounter on a day-to-day basis.

The comments on the draft Bill follow the order of the clauses of the Bill itself and have been drawn from information provided by SFE's members.

2. DEFINITION OF PERSONS WHO LACK CAPACITY ETC (CLAUSES 1-3)

The following issues will need further consideration:

2.1 Under clause 1(1) a person can be treated as lacking mental capacity if he is unable to make a decision for himself because of "impairment of or a disturbance in the functioning of the mind or brain". It is unclear how wide this definition is intended to be. Could it, for example, encompass the possibly temporary effect of drugs or alcohol? More importantly, to what extent does this definition of capacity take precedence over, dispense with or otherwise revoke the existing common law tests for various types of legal capacity; testamentary capacity, capacity to make gifts, capacity to instruct solicitors in litigation/other matters, make an EPA etc? Is there intended to be one over-riding statutory test for these matters or will the common law tests be used together with the statutory test? If the latter is to be the case, it appears that a common law test could have an additional element added. For example, the *Banks v Goodfellow* test for testamentary capacity does not require the testator to have considered the reasonably foreseeable consequences of either deciding or failing to decide which clause 2(5) of the Bill does require. Under *Banks v Goodfellow*, the testator does not need to understand what would happen should they decide not to make a Will and consequently the effect of the intestacy rules on their estate, but the Bill would require this.

¹²⁷ Not printed.

2.2 Under clause (2)(1)(d), a person will be treated as unable to make a decision if he cannot communicate the decision. Various examples of how that decision could be communicated are given in the notes. What is intended to be the position however in relation to a person who cannot communicate as a result of physical paralysis which cannot be demonstrated to be referable to an impairment or disturbance in the functioning of the brain? That person would fulfil only part of the clause 1(1) definition—he would be unable to make a decision for himself because he could not communicate that decision—but it would be unclear that he would be unable to decide as a result of the impairment of or disturbance in functioning etc.

2.3 Under clause 2(3) a person will not be treated as unable to make a decision unless all practicable steps to help him do so have been taken without success. Clause 22 of the Commentary gives examples of the steps which could be taken to help somebody make their own decision and mentions that this is an area which the Code of Practice will cover. It would, however, be sensible for the word “reasonable” to be inserted between “all” and “practicable”. “Practicable” could obviously be construed as encompassing the concept of reasonableness but it would be more sensible to make this clear and would assist those trying to assess the lengths to which someone should go to achieve communication.

2.4 Clause 2(4) indicates that the fact a person is able to retain the information relevant to a decision for a short period only does not prevent him from being regarded as being able to make that decision. There is a concern that this does not provide protection in particular to a client with dementia who may, for example, recall they need to pay a bill but once paid, forget within a short period of time that it has been paid and so pay again. This is an area in which, again, the Code of Practice could give guidance.

2.5 Clause 3—presumption against lack of capacity. Although clause (3)(1) restates the existing common law presumption of capacity, the wording “unless it is established that he lacks capacity” is unclear. To whose satisfaction should this be established?

3. BEST INTERESTS (CLAUSE 4)

The “best interests” test in clause 4 is effectively a codification of well established common law principles which are now related to making decisions for incapacitated adults. Although SFE welcomes the statutory requirement to act in an incapacitated person’s best interests as a useful focus of the mind of whoever is seeking to make a decision for an incapacitated person, there are a number of issues which require further consideration and clarification:

3.1 The listed factors to be taken into consideration when determining best interests are not as wide as those contained in previous recommendations. The legislation in Scotland, for example, has a concept of “general principles” intended to cover the same ground which could be argued to be less paternalistic.

3.2 It is unclear how the “best interests” test is intended to be applied when the matter under consideration is the making of a Will, Settlement or a gift in favour of a third party. This type of action could only rarely be said to be directly in the best interests of the incapable person if it results in immediate financial reduction even if the plan is for a saving of tax later on. Under the Mental Health Act 1983, the test applied by the Court of Protection is whether the patient would make the gift/settlement if they were of full capacity and properly advised (cf *Re D (J)* in respect of Wills). Obviously the Court would never make a gift or settlement which would be detrimental to the patient but that is very different from saying that making it must be in the best interests of the person who lacked capacity.

3.3 It is also unclear whether the “best interests” test is intended to be subjective (ie what the incapable person in question would consider to be in his best interests) or objective (ie what a reasonable person in the position of the incapable person would conclude to be in his best interests). Logically, the test should be a subjective one to follow the existing case law in relation to financial decision making by the Court of Protection but this needs to be clarified.

4. GENERAL AUTHORITY (CLAUSES 6 & 7)

4.1 Although SFE welcomes the statutory General Authority (GA) as a practical solution to the need for day to day authority for decision making, the welcome is a cautious one. It has been reported on a number of occasions that financial abuse under the existing EPA arrangements is probably happening in some 20% of cases and the proportion may be much higher, bearing in mind the large number of EPAs which are not registered. Where there is no EPA or receivership order, presently no individual has the power to act for another and it is impossible to assess what level of financial abuse is already ongoing as where there are no formalities there is no way of monitoring the prevalence of abuse. The GA is intended to apply in hospitals, care homes, day centres, private homes and any other public place or setting where services are provided but there is little in the Bill to provide safeguards against the kind of abuse which, even anecdotally, it is clear is going on now.

4.2 Clause 6 authorises a person to carry out an act when providing “any form of care”. The word “care” itself is not defined and could be a very widely drawn concept. To take an extreme example, a carer providing meal making services for an incapable person might decide that an incapable person’s kitchen is not suitable to provide the kind of meals which they believe it is in the best interests of the incapable person to receive and

incur expenditure (see 4.4 below) on behalf of the incapable person in purchasing a new cooker, microwave, dishwasher and other expensive kitchen equipment. They would do this believing they were acting in the best interests of the incapacitated person but where is the line to be drawn?

4.3 To use a GA, there is no need for a Court to have selected the decision maker and set parameters for decision making. Neither have these issues been determined by the incapable person themselves as would be the case under an EPA or LPA. In a GA situation, the decision maker would be empowered to make decisions until such time as they are challenged and so it is doubly important that safeguards and parameters are set in an identifiable way.

4.4 It is of concern that under clause 6(2) a person acting under a GA could carry out an act involving expenditure and as part of this, pledge the incapacitated person's credit for the purposes of the expenditure and apply money belonging to the incapacitated person to meet it. It is doubtful in any case that any financial institution would act on the basis of a GA to enable a person to operate a bank account or raise money on the security of an incapacitated person's property; our members already experience difficulty regularly in arranging for banks etc to accept EPAs. There is also no requirement that the person able to exercise these financial powers under a GA is themselves financially prudent. At present, an attorney under an EPA or a receiver cannot be a bankrupt but there is no such limitation on someone acting under a GA.

4.5 It appears under clauses 6(4) and 7(2) that although the GA does not authorise a person to do an act which conflicts with a decision made either by a donee of an LPA or a deputy, a person will be able to exercise a GA notwithstanding that another person actually holds an LPA or is a deputy providing that those persons have not made an actual decision. This seems likely to cause significant confusion. Surely where a person with capacity has appointed an attorney to make a decision for him or the Court has appointed a deputy, no other person should be permitted to act under the GA without having first taken all reasonable steps to contact the attorney or deputy and discuss and clear the decision proposed to be made with them?

4.6 The position of third party providing goods or services requested under a GA is not clear. They may have no knowledge of the appointment of an attorney or a deputy or any contrary decision made by them.

5. LASTING POWERS OF ATTORNEY (CLAUSES 8-13 INCLUSIVE)

5.1 SFE members are well aware of the existing problems that surround EPAs as they regularly draft them, advise on them, and consider the capacity of their clients to make them. One of our members has commented "EPAs are not understood well by the general public and the fact that you can buy them in a bookstore . . . I believe is very misleading . . . The fact that they can be completed by anyone and then used is very worrying. From my experience they complete these forms when persons are already mentally incapable and then unfortunately we all know the results". SFE members have therefore raised a number of points concerning LPAs.

5.2 ATTORNEY'S POWERS AND RESTRICTIONS

A donor under an LPA will be able to grant a wider range of powers to their attorney than under an EPA. An attorney can be granted power over personal welfare and property and affairs. SFE welcomes this development but with caution. It may be appropriate for the "financial" attorney to make welfare decisions or the LPA may need to be restricted or more than one prepared dealing with separate issues. This has cost implications for clients as each new LPA will need to be registered and have a capacity certificate—each with attendant cost.

5.3 FORM OF THE LPA

A number of our members have commented on the difficulties with the current prescribed form of EPA. Obviously the new form of LPA will be specified by regulation (not yet available) however it is anticipated that there will be prescribed information in the same broad form as the current EPA. One of our members has commented in relation to the current form that "the wording on the front of the current documents is also quite difficult to explain to clients, especially number 7 which states "become or are becoming"—what does this really mean to the general public?" and another suggests that Plain English is used which it is felt would reduce abuse as donors would be clearer as to the effect of the power. Schedule 1 Part 1 paragraph 2 specifies matters to be covered in the prescribed form. SFE would welcome consultation on it when a draft is available.

5.4 NOTIFIABLE PERSONS

Although Schedule 1 Part 1 paragraph 2(c) provides that the donor may state in the instrument there are no persons whom he wishes to be notified of any such application, our members have concerns about this. It is accepted that there are those donors who have no relations or close friends to notify however our members regularly encounter situations which, for example, one of three children is appointed as attorney and the other two do not find out about it until registration is applied for under the current EPA system. Children not appointed (sometimes correctly, sometimes not) feel disgruntled about this and it would be sensible for

there to remain a requirement for notification of, perhaps, near blood relations. Such notification obviously will now take place at the point of registration whilst the donor still retains capacity so that they can explain their selection of attorneys.

5.5 IDENTITY OF DONEES

Clause 9(1) provides that a donee can only be as trust corporation where the power relates to property and affairs. In practice if the trust corporation were managing a donor's finances they might need to be involved in welfare decisions (although not giving or refusing consent to medical treatment). This would mean that they would have to rely on applying to the Court for appropriate authority or somebody exercising a general power. This would by its nature incur additional expense and delay.

5.6 REGISTRATION, CAPACITY ASSESSMENT AND COSTS

An instrument will not be a valid LPA until it has been registered and therefore the present system of acting under an unregistered EPA will no longer exist. One of our members has expressed concern that registration on creation could be "ridiculously bureaucratic, frustrating and time consuming etc" and others have commented that EPAs are currently used frequently for those quite capable but who simply need a document to assist them with a house move, cover their finances in relation to a holiday or a gap year for a student. SFE is concerned that the requirement for immediate registration, with its cost, will deter people from making LPAs which must be a bad thing, considering the issues of abuse. One of our members commented "I would regret anything that encouraged clients to postpone putting their affairs in order. An active LPA regime, where people are encouraged to create LPAs, would presumably reduce the amount of ... receiverships, so it is in everyone's interests to ensure LPAs are an attractive proposition".

The same comment could be made about the requirement in Schedule 1 Part 1 paragraph 2(e) concerning the requirement for a certificate signed by a person of prescribed description as to the capacity of the donor. Additionally it is by no means clear whom a prescribed person should be and this seems to be an area in which much more guidance is required. There has been judicial comment in at least one recent testamentary capacity case to the effect that the evidence of a solicitor as to the capacity of testator is as useful as that of a doctor even though it is accepted that the solicitor is not medically trained. That having been said, solicitors do not have specific training in the assessment of capacity and there would be concern as to what training would be necessary for a solicitor to be sufficiently qualified to assess a client and give such certificate.

The costs of giving such a certificate are obviously a consideration as well. Added to the registration fee, they could represent a significant outlay on behalf of the client in making an LPA.

5.7 ONE LPA OR MORE THAN ONE

It has in the past been common for more than one EPA to be made although it has never been completely clear whether a later EPA was to revoke an earlier one. This matter is also not clear as far as LPAs are concerned. The bills should clarify whether more than one LPA with the same scope can exist at the same time. If it does, will the Public Guardian register both? What will the PG's view be if there was in existence one LPA covering both welfare and financial matters and one covering only welfare matters?

5.8 DELEGATION

Clause 9(8) does not permit the donee of an LPA to appoint a substitute or successor but can appoint a person to replace the donee on the occurrence of death, bankruptcy or disclaimer of the donee or divorce of donor or donee. The Act does not, however confirm specifically that this is the only substitute decision making power permitted under an LPA and that an attorney cannot otherwise delegate his or her decision making power. It is accepted that the restriction on delegation is a general provision of existing agency law but if a detailed statutory framework for LPA is available, this should be made clear.

5.9 REVOCATION

Clause 12(5) does not provide power for the Court to remove a donee and revoke the power. The Court is given this power in clause 21 (4) but only where the donor has lost capacity. It might be difficult to think of occasions in which the Court might require the power to revoke an LPA and remove a donee where the donor does retain capacity however such occasions might arise, for example, the donor retains capacity but is being unduly influenced by the donee.

Clause 12 should make specific provision as to how an LPA is to be revoked—should writing be required? What is the position after revocation but before registration has been cancelled? Provision is also required as to notifying a Public Guardian and amending the Register. Finally, perhaps the appointment of a deputy with either the same or overlapping scope should revoke the appointment of an attorney under an LPA unless specially provided to the contrary in the appointment.

5.10 LPAs AND GIFTS

Although the “best interests” test is not specifically referred to in clause 11, clause 4(1) says that all decisions made under the Act are subject to the test. Clause 11 clearly seeks to deal with some of the issues which have arisen under Section 3(4) EPAA 1985 but some other issues still arise. It is not clear if clause 11 can be used to permit an attorney under an LPA to maintain himself or a third party who could reasonably expect to be maintained by the incapacitated donor. This could encompass a spouse, minor child, dependent co-habitee or even an adult child who having been independent subsequently became incapable of supporting himself or herself. On the basis of the limited scope of clause 11, it is likely that more applications for single orders will be made to the Court of Protection not less.

5.11 ACCOUNTS—SEE 7.2 BELOW

6. RESTRUCTURED COURT OF PROTECTION (CLAUSES 14 & 15, 34-37)

6.1 It is not entirely clear from clause 37(1) exactly what powers of the High Court the Court of Protection will have. The reference to High Court powers is not specific enough and the powers which the Court of Protection requires should be specified.

6.2 The Court itself will, in any case, need to have special resources to train judges. Although nobody below the level of District Judge can apply to be a Judge of the Court of Protection, the unusual jurisdiction and procedures of the Court means that there will be few existing district judges who have the skills to become Court of Protection Judges and special training will be required.

7. DEPUTIES (CLAUSES 16-20)

7.1 While it is welcomed that the individual be able to continue to have appropriate control over their affairs, limiting the scope and duration of the authority of a deputy in clause 16(4)(b) in practice will almost certainly cause confusion with financial organisations as to when and who can sign financial papers. There could be some provision for a general authority on similar terms as an LPA when dealing with finances and affairs which is for a fixed period but renewable. Additionally, the more times the deputies return for a court authority the more the delay and expense. Although it is understood that the decision of the Court is to be preferred to the appointment of a deputy to avoid the need to interfere more than required in decisions, there are cases where a person’s decision making powers vary considerably on a week by week basis, particularly if they are suffering from illnesses which recur from time to time or which are managed through drugs or which have a seasonal nature. In such cases, the appointment of a deputy should be preferred to provide consistency. Similarly, in the case of progressive dementias of the elderly, where a particular point has been passed, it is unlikely that the incapable person will ever be in a position to make any decision other than a very modest nature.

7.2 It is noted that under clause 19(9) a deputy may be required to submit to the Public Guardian such reports at such times and at such intervals as the Court may direct but there is no automatic requirement for the submission of accounts. SFE would strongly urge that deputies should be required to submit accounts on an annual basis to the Court or the Public Guardian or a nominated person unless that requirement is expressly dispensed with. Holders of financial LPAs should be subject to having to submit accounts if requested and the Public Guardian should select some attorneys each year and require accounts from them. This would encourage high financial standards and discourage abuse.

7.3 Clause 20(3) does not exclude the deputy having a power to make gifts. It is unclear whether a deputy is intended to be given these powers.

7.4 The width of clause 20(4) is concerning. Although it is unlikely that a deputy would be appointed when a LPA already exists with the same or similar scope without that LPA being revoked by the Court, a decision might have been made by an attorney under that LPA which a deputy might then wish to change which Clause 20(4) does not permit.

7.5 Clause 19(1) does not allow for a trust corporation deputy to be able to make any welfare decisions, in particular where someone should live. This would mean that they would have to rely on an application to the Court for the appropriate authority which would by its nature incur expense and delay. It may be of benefit for a trust corporation to have the power to make welfare decisions but it would not seem appropriate for this to extend to giving or refusing consent to medical treatment.

8. ADVANCE DECISION TO REFUSE MEDICAL TREATMENT (CLAUSES 23-25 & 32)

8.1 Clauses 23 to 25 basically codify the present common law position concerning the right of a competent adult to refuse treatment, both at the time when that adult has capacity and at some future time when capacity may have been lost. Cases such as *Re C* (1993) and *Re T* (1992) confirm the right to make such a refusal and specify the mental capacity required to make such a refusal and conditions precedent for one to be valid.

Various points arise, however, from the provisions of the draft bill.

8.2 The only formalities specified in clause 23 for what is described as “the decision” are that it has to be made by a person aged 18 with the necessary capacity. There appears to be no requirement for the decision to be expressed in writing and no formalities specified for any such writing. This indicates that advance decisions could be made orally however there are no specific formalities for such an oral decision. Some US States allow for oral advance directives but, considering the potentially informal nature of the making of a directive in this way, specify particular formalities as a safeguard.

8.3 Clause 23(1) refers to the necessary capacity to make an advance decision and the lack of capacity to consent to the carrying out of a continuation of such treatment. On the basis that the definition of persons who lack capacity in clause 1(1) is expressed to apply for the purposes of the Act, it is assumed that both the capacity to make an advance decision and the lack of such capacity to give consent to treatment are now both to be assessed in accordance with clause 1(1) rather than in accordance with previous case law tests (eg *Re C*).

8.4 An advance decision will only be effective if it is both valid and applicable (clause 24). An advance decision will not be applicable if circumstances exist which were not anticipated by the maker of the decision at the time when it was made and which would have affected his decision had he anticipated them. This can potentially make advance decisions difficult to operate in an area of medical practice which is rapidly changing. For example, many new treatments for Alzheimer’s has been discussed and tested in recent years. A person with dementia seeking to make an advance decision may well have to be advised that the developments in medical practice are such that an advance decision may not be found to be applicable at the time when capacity has been lost.

8.5 Clause 24(5) indicates that advance decisions may be used to refuse life sustaining treatment. Although this term is not defined, it seems likely that it would cover the same ground as the definition of “basic care” used by the Law Commission in Report 231 (1995) and other subsequent reports. All the reports agreed that to allow a refusal of basic care would make caring for an incapacitated person extremely difficult for their medical advisers and therefore there ought to be a limitation on advance decisions that this kind of care (such as keeping the patient warm, clean and controlling distressing systems) should not be able to be refused. This has now been changed in the bill but it is not clear why.

9. ILL TREATMENT AND NEGLECT (CLAUSE 31)

9.1 SFE welcomes a new offence of neglecting or ill treating a person who lacks capacity. This is however a criminal offence and will be subject to the criminal standard of proof of beyond reasonable doubt and it is unclear how the new offence will fit with powers of the Court of Protection and the Public Guardian. Clause 39 gives the Court of Protection powers to call for reports when considering issues in proceedings. The reports are to be made by Public Guardian or the Lord Chancellor’s Visitors. It does not seem from clause 48 that the Public Guardian has a duty to investigate or alert the Court in cases of suspected abuse. The Public Guardian’s functions are limited to supervising donees of LPA and deputies, directing Lord Chancellor’s Visitors to visit and report and dealing with complaints about the way in which a donee of a LPA or a deputy has exercised their power.

9.2 In general, it would be more understandable if all the protection and safeguard provisions of the bill were grouped together. At present, they appear in a number of different sections relating to the different types of decision maker and are therefore hard to assess as a group.

September 2003

116. Memorandum from ALERT (MIB 933)

ALERT is an association of those who oppose the legalisation of euthanasia in all its forms. We are very concerned that whilst this Bill is intended to protect persons who lack capacity to make decisions, in its present form it could be used as an excuse for a doctor or one given power of attorney to shorten or end a person’s life deliberately.

In particular we feel that:

1. Temporary incapacity could be deemed a reason for someone other than the person lacking capacity to make a decision, which could prove lethal or otherwise prevent that person from recovering his or her decision-making capacity.
2. The weight given in the Bill to “living wills” or advance refusals of treatment may prevent doctors and carers from treating their patient conscientiously, since they could be expected to follow to the letter a statement made by the patient at a time when the present circumstances could only be imagined, and an informed decision was impossible.

3. Furthermore, if they requested neglect of ordinary life-sustaining care they would be encouraging assisted suicide or deliberate killing by omission, both of which are contrary to human and medical ethics, presently illegal, and harmful not only to the patient but to the profession of medicine and to society at large.

ALERT has requested the opinion of Richard Gordon, QC, on the compatibility of the Mental Incapacity Bill with the European Convention on Human Rights. I enclose his opinion, which I ask you to put before the Committee as the submission from ALERT.

Pt 1: INTRODUCTION

1. I am instructed to advise on behalf of ALERT as to whether any provisions of the latest version of the Mental Incapacity Bill ("MIB") are incompatible with the European Convention on Human Rights ("ECTIR").

2. The remainder of this Opinion is structured as follows. Pt 2 outlines the content of MIB material to the questions that I am invited to consider. It also foreshadows areas of potential ECHR concern. Pt 3 identifies the legal issues that I consider are relevant for consideration. Pt 4 analyses these issues and Pt 5 sets out a summary of my conclusions.

Pt 2: AN OUTLINE OF THE BILL AND ECHR CONCERNS

Overview

3. In general terms, MIB is concerned to ensure that persons lacking legal capacity to make decisions for themselves are provided with an effective decision-making process whereby decisions are made in their best interests.

4. It is, undoubtedly, the case that decision-making on behalf of incapacitated persons has generated much controversy. In particular, the decision of the House of Lords in *R v. Bournewood Community and Mental Health NHS Trust, ex p. L* [1999] A. C. 458 ("Bournewood") highlighted many of the deficiencies that existed (and continue to exist) in respect of protecting vulnerable people who lack the requisite relevant decision-making capacity.

5. The fact that the current state of the law is, in relation to incapacitated persons, inadequate does not, of course, mean that the intended statutory reforms contained in MIB are ECHR compliant.

6. MIB focuses, for present purposes, on the following key areas: (a) the general authority to care for persons without capacity and restrictions on it including 'advance decisions' (clauses 6-7 and clauses 23-25), (b) lasting powers of attorney (clauses 8-13 and Sch 1), and (c) powers of the Court (clauses 14-22).

7. Before outlining these areas it is important to bear in mind that, under clause 4(1)MTB:

"Where under this Act any act is done for, or any decision is made on behalf of a person who lacks capacity, the act must be done or the decision made in the person's best interests."

8. The concept of a lack of "capacity" is addressed in clause 1. By clause 1(1) "a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of or a disturbance in the functioning of the mind or brain". Clause 1(2) clarifies that it is immaterial whether the impairment/disturbance is permanent or temporary.

9. Best interests is a judgment to be made in respect of acts or decisions in relation to persons lacking capacity for each of the key areas identified above. That concept is not defined in MIB but clause 4(2) specifies the matters to which "regard must be had" in deciding what is in a person's best interests. These matters are:

- (a) Whether the person is likely to have capacity in relation to the matter in question in the future.
- (b) The need to permit and encourage participation by that person, or to improve his ability to participate, as fully as possible in anything done for and any decision affecting him.
- (c) (So far as ascertainable) the person's past and present wishes and feelings and the factors which he would consider if he were able to do so.
- (d) (If it is practicable/appropriate to consult) the views as to the person's wishes and feelings and as to what would be in his best interests of a number of identified persons.
- (e) Whether the purpose for which any action or decision is required can be as effectively achieved in a manner less restrictive of his freedom of action.

10. Plainly, this list is not exhaustive. Nor does not it appear to constrain the decision-maker. It contains important factors to which regard must be had. The extent, if any, to which clause 4 and its inclusion of particular factors relevant to 'best interests' is in tension with the ECHR can best be determined by reference to the relevant acts or decisions that clause 4 underpins and the concept of 'lasting power of attorney'. These I outline below.

11. It should also be noted that clause 4(4) provides that “In the case of anything done or a decision made by a person other than the court it shall be a sufficient compliance with [the best interests objective in clause 4(1)] If that person reasonably believes that what he does or decides is in the best interests of the person concerned.”

Care of Persons without Capacity/Restrictions/Advance Decisions

12. Clause 6(1) M113 contains a general authority for any person to do an act when providing any form of care for another person’ (“P”) provided either that P lacks or that the person reasonably believes that P lacks capacity in relation to the matter in question and that it is, in all the circumstances, reasonable for that person to do the act. Clause 6(6) makes it clear that the general authority is subject both to other provisions of MIB and also to clause 4 on best interests (see above).

13. Clause 7 MIB places certain restrictions on the operation of the general authority. Thus: (i) neither force nor the threat of force may be used to secure an act which P resists and/or (ii) P’s liberty of movement may not be restricted ‘unless the person reasonably believes that it is necessary to do so to avert a substantial risk of significant harm to P’ (clause 7(1)).

14. Notwithstanding clause 7(1) it seems (see below) that a person with lasting power of attorney (or a Court-appointed deputy) could, under clause 7(2), veto action by a person using force or the threat of force with the intent of averting a substantial risk of significant harm to P unless such action fell under clause 7(3) (action necessary to avert death/serious deterioration whilst an Order is sought from the Court).

15. Materially, therefore, there has been introduced by somewhat convoluted provisions in MIB a new care regime that considerably restricts the very wide form of “necessity” that the House of Lords had endorsed in *Bournewood*.

16. Clauses 26-28 exempt certain specified forms of treatment/procedure (as, eg, infertility treatment) from the operation of MIB.

17. Clauses 23-25 endorse the concept of ‘advance decisions to refuse treatment. Where a person, aged 18 or over, possessing capacity has indicated a refusal of specified medical treatment at a later time and in such circumstances as he may specify and at a point when he lacks the necessary capacity to give consent then the specified treatment is not to be carried out or continued (see clauses 23(1) and 25(1)).

18. No liability is imposed on a person for withholding treatment/procedure if he believes that there is a relevant valid advance decision and that there are reasonable grounds for believing that such advance decision applies to the situation (see clause 25(3)). Conversely, there appears to be at least potentially civil liability for carrying out or continuing treatment unless a person does not know and has no reasonable grounds for believing that an advance decision exists which is valid and applicable to the treatment (see clause 25(2)).

19. There are no specified formalities (or system of registration) for the making of an advance decision and (see clause 23(2)) it may be expressed in broad terms or non-scientific language. It may apply to all forms of treatment although, by clause 24(5), an advance decision is not applicable to life-sustaining treatment unless P specified that his decision was not to apply to such treatment.

20. Clause 25(5) provides that nothing in an apparent advance decision precludes a person from providing life-sustaining treatment or doing any act reasonably believed to be necessary to prevent a serious deterioration in P’s condition while a ruling as respects any relevant issue is sought from the Court.

Lasting Powers of Attorney

21. This new concept, replacing enduring power of attorney, is covered in MITB in clauses 8-13 and Schedule 1 MIB. It is, in company with all other powers under MJB, exercisable subject to clause 4 above (see clause 8(4)(a)). In other words, a person exercising lasting powers of attorney must act in P’s best interests. It appears to be sufficient compliance if the donee of the power reasonably believes that what he does or decides is in the best interests of the person concerned (see clause 4(6)). However, unlike a person exercising the general power in clause 6 it does not, in all the circumstances, appear to have to be reasonable for the donee to do the act (cf clause 6(1)(b)).

22. Essentially, the concept enables a person (the donor) to create a power of attorney in another person (the donee) that enables decisions to be made on behalf of the donor by the donee as to P’s personal welfare or specified matters concerning P’s personal welfare and P’s property and affairs or specified matters concerning P’s property and affairs and which includes authority to make such decisions in circumstances where P no longer has capacity (see clause 8(1)).

23. The different species of requirements for valid execution of lasting powers of attorney are contained in clauses 8-9 and Schedule 1. Briefly:

- (a) There must be compliance with a prescribed form, though immaterial deviation is permissible (Schedule 1 paras 1-3)¹²⁸
- (b) There are requirements of age/status as between donor and donee (clause 9). In general, however, any person over 18 may become a donee provided (at least in relation to matters concerning the donor's property and financial affairs) that they are not (or do not become) bankrupt.
- (c) There are also general requirements as to registration (Schedule 1 Pts 2-3).

24. Clauses 10-11 contain provisions relevant to the scope of a continuing power of attorney. In particular, the donee is not authorised use or threaten force to secure the doing of an act which P resists or to restrict P's liberty of movement whether or not P resists unless P lacks or the donee reasonably believes that P lacks relevant capacity and the donee reasonably believes that it is necessary to do the act to avert a substantial risk of significant harm to P.

25. Clauses 21-22, in particular give certain powers to the Court in relation to the validity and operation of lasting powers of attorney, including exercising powers of supervision over the conduct of the donee and cancelling registration.

26. Other provisions of relevance include the creation of an officer known as the Public Guardian (clause 47) and the significant responsibilities that he has in respect of lasting powers of attorney (see clause 48) including the supervision of donees of such powers and general control of the register (with powers of cancellation).

OTHER RELEVANT PROVISIONS

27. The Court has supplementary power under MIB to make declarations (clause 15) and other Orders in respect of capacity and advance refusals (clause 37). It may make decisions in respect of a person's health and welfare or appoint a deputy although, by clause 16(4)(a)) the Court's decision over that of a deputy is accorded statutory preference.

28. Clause 26 does not allow decisions to be made on behalf of an incapacitated person in respect of a number of specified matters—none of them, however, include the decision to die.

29. By clause 30 the Lord Chancellor (sic) has power to prepare a Code of Practice on what constitutes capacity and how persons with relevant functions under MIB should act.

30. The relevant "Court" under MIB is the Court of Protection (see clause 34). Access to the Court is governed by clause 40 which, generally, requires leave to be given for applications to be made to it. The matters to which the Court may have regard in giving leave are set out in clause 40(3) and include sufficient connection with the subject matter and reasons for the application. No leave is required (see clause 40(1)) for an application to the Court by or on behalf of a person who is alleged to be (or is) without capacity, by the donor or donee of a lasting power of attorney to which the application relates, by a Court appointed deputy, by a person named in an existing Order, or by a person with parental responsibility for such person if under 18.

ECHR CONCERNS

31. MIB gives rise to three main areas of ECHR concern. Briefly stated, they are in my view those issues relating to:

- (a) The right to life contained in Article 2.
- (b) The right to protection from inhuman and degrading treatment under Article 3.
- (c) The right of access to a court provided for in Article 6.

32. Put shortly, and as highlighted above, MIB contains a series of provisions that are ostensibly designed to put persons lacking capacity (so far as is possible) on a par with those who possess autonomy. The difficulty with this kind of endeavour is that, unless the statutory mechanisms are very carefully drafted, there is very real potential for abuse, exploitation and violation of fundamental Convention rights.

33. In my view, for the reasons set out below, there are Convention concerns as to the drafting of MIB although it is an improvement on the version on which I previously advised.

PT 3: THE LEGAL ISSUES

34. The most directly relevant issues of law seem, therefore, to me to be reducible to the following general questions:

- (a) Are there any provisions of MIB that are, at least potentially, incompatible with Article 2 ECHR (taken by itself or in conjunction with other ECHR provisions, most notably Article 6)?

¹²⁸ The Court has certain powers if satisfied that the parties intended to create a lasting power of attorney (see Schedule 1 paragraph 3(2)).

(b) Are there any provisions of MIB that are, at least potentially, incompatible with Article 3 ECHR (similarly considered)?

(c) Are there any provisions that are potentially incompatible with any other provision of the ECHR?

35. I will address these general questions in turn.

Pt 4: ANALYSIS

ARTICLES 2 AND 6 ECHR AND DOMESTIC LAW

The General Position under Article 2

36. Article 2.1 ECHR provides (materially) thus:

“Everyone’s right to life shall be protected by law. No one shall be deprived of life intentionally . . .”

37. Article 2 ECHR, therefore, contains a negative restraint on the State but also requires the State to take active steps for the protection of life: a so-called positive obligation.

38. The *locus classicus* is the decision of the Strasbourg Court in *Osman v United Kingdom* (1998) 29 EHRR 245. The Court stated that:

“115. The Court notes that the first sentence of Article 2(1) enjoins the State not only to refrain from the intentional and unlawful taking of life, but also to take appropriate steps to safeguard the lives of those within its jurisdiction. It is common ground that the State’s obligation in this respect extends beyond its primary duty to secure the right to life . . .”

39. A person possessing the requisite capacity to make decisions for themselves may refuse to be treated. However irrational or otherwise unreasonable the decision is, it must be respected.

40. But the position is different in relation to persons lacking legal competence. There, the position in law is that a doctor may treat a patient who is incapable of giving consent, provided that the treatment is in the patient’s best interests.

41. In domestic law there is a strong presumption that medical practitioners should take all steps capable of preserving human life. But, according to House of Lords authority in *Airedale NHS Trust v. Bland* [1993] A. C. 789, 867 (“Bland”):

“The doctor who is caring for . . . a patient cannot . . . be under an absolute obligation to prolong his life by any means available to him, regardless of the quality of the patient’s life.

42. Importantly, it has also been held that where the continuance of medical care of a patient in a permanent vegetative state would not be in his best interests, there was no breach of Article 2 if that care was withdrawn (see: *NHS Trust A v M, NHS Trust B v H* [2001] 2 W.L.R. 942) (“M & H”).

43. There is, then, if *M&H* (and *Bland*) are right a crucial difference between acts and omissions. A positive act that causes a person’s death is murder. But the position is different where death is caused by omission or where the primary purpose is not to cause death (see, especially, in this respect *Bland*).

44. Many do not agree with the ratio in *Bland* and *M&H* and with the analytic distinction between acts or omissions in the present context. As Butler-Sloss P observed in *M&H* (at p. 949, paragraph 19) “the question of discontinuing artificial nutrition and hydration to a patient in a permanent vegetative state has not yet arisen in the European Court of Human Rights. . .”

45. However, in that context Article 2 was, fully, analysed in *M&H* as follows:

(a) Article 2 clearly constitutes a negative obligation on the State to refrain from taking life intentionally. It also imposes a positive obligation on the State to give life-sustaining treatment in circumstances where, according to responsible medical opinion, such treatment is in the best interests of the patient. It does not, however, impose an absolute obligation to treat if such treatment would be futile.

(b) An omission to provide treatment by a medical team will only be incompatible with Article 2 where the circumstances are such as to impose a positive obligation on the State to take steps to prolong a patient’s life. (Butler Sloss P clarified that her judgment was only addressing the situation where treatment was to be discontinued and was not concerned with acts by doctors or other members of the clinical team which might have the effect of shortening life).

(c) The quality of life may, under Article 2, be relevant to the clinical assessment of whether it is in the patient’s best interests for treatment to continue but does not form part of the question whether this is an intentional deprivation of life within the meaning of Article 2.

46. For the purpose of this Opinion and for the purpose of analysing the deficiencies in MIB, I must take the law to be as stated in *M&H*

THE RELEVANCE OF PROHIBITING ASSISTED SUICIDE

47. The prohibition against taking active steps to end life is one that is enshrined in Article 2 ECHR. A person may decide to end his or her own life but it is certainly consistent with Article 2 that the State does not facilitate third party assistance. The decriminalisation of suicide may be said to reduce suicide by encouraging individuals to seek help. However, the prohibition against assisting suicide contained in s. 2(1) of the Suicide Act is entirely lawful because it operates to prevent the crime of murder.

48. In *Pretty v United Kingdom* (Application No 2346/02) the European Court of Human Rights made it clear that mercy killing by a third party, albeit at the behest of the person affected, was legitimately prohibited by the State under Article 2 ECHR. The Strasbourg Court observed thus:

“39. The consistent emphasis in all the cases before the Court has been the obligation of the State to protect life. The Court is not persuaded that the “right to life” guaranteed in Article 2 can be interpreted as involving a negative aspect . . . it is unconcerned with issues to do with the quality of life or what a person chooses to do with his or her life . . . nor can it create a right to self-determination in the sense of conferring on an individual the entitlement to choose death rather than life.

40. The Court accordingly finds that no right to die, whether at the hands of a third person or with the assistance of a public authority, can be derived from Article 2 of the Convention. It is confirmed in this view by the recent Recommendation 1418¹²⁹. . .

41. The applicant has argued that a failure to acknowledge a right to die under the Convention would place those countries which do permit assisted suicide in breach of the Convention

[E]ven in circumstances prevailing in a particular country which permitted assisted suicide, that would not assist the applicant in this case, [with] the very different proposition—that the United Kingdom would be in breach of its obligations under Article 2 if it did not allow assisted suicide . . .”

THE RELEVANCE OF ARTICLE 6 ECHR

49. Article 6(1) ECHR provides (materially) that:

“In the determination of his civil rights and obligations or of any criminal charge against him, everyone is entitled to a fair and public hearing within a reasonable time by an independent and impartial tribunal established by law.”

50. Self-evidently, in order to obtain a hearing by a Court there must be access to that Court. The right of access to a Court is, therefore, intrinsic to—or necessarily implicit in—the express rights guaranteed by Article 6: see *Golder v UK* (1975) 1 EHRR 524. It is also well established that even a temporary impediment on access may violate this right.

51. Clearly, the right to protection of life under Article 2 (in both the positive and negatives senses identified above) and/or the right to a Court hearing for the determination of that civil right and the obligation not to be assisted to kill oneself are embraced by (respectively) the positive obligations under Article 2 and the due process rights under Article 6.

INCOMPATIBILITY OF MIB AND ARTICLES 2/6 ECHR

52. In my opinion there are at least two major deficiencies in MIB which contravene the obligations enshrined in Article 2 taken in conjunction with the right to access to a Court under Article 6.

53. The deficiencies are in relation to: (a) the extensive power conferred upon persons under the general authority and, in particular the powers conferred on the donee of lasting powers of attorney, and (b) MIB’s treatment of advance decisions to refuse treatment coupled, in each case, with the limitations on access to the Court contained in MIB clause 40.

DONEE’S LASTING POWERS OF ATTORNEY AND ARTICLES 8–13 AND SCHEDULE 1

54. The difficulty with MIB, in this respect, is that its provisions—taken together—fall short of the likely content of the positive obligation in Article 2 to give practical and effective protection to the right to life of a person without capacity and/or to the right to determination by a Court of the civil right/obligation vested in such person not to have his/her death assisted by a third party by positive acts.

55. Lasting powers of attorney enables the person on whom the power has been conferred to exercise a relevant power provided, only, that he or she reasonably believes the donor to be without the requisite capacity (see clauses 8(4)(a) and 4(4)). There is no proposed statutory check on the assumed exercise of power by the donee beyond the clause 40 right of access to the Court and general supervision of the donee by the Public Guardian (see above and clause 48(1)(c)-(d)). So, if the donee has an unreasonable (and, perhaps,

¹²⁹ This is a reference to the Council of Europe’s Recommendation 1418 (1999) on the Protection of Human Rights and the Dignity of the Terminally Ill and Dying.

unjustified) belief in a donor's lack of capacity there is at least potential scope for abuse of power. Nor is there any specific statutory threshold by which the donee's reasonable belief falls to be tested at the time of the asserted assumption of belief

- (a) Armed with at least an asserted reasonable belief in the donor's incapacity, the donee may, amongst other things, refuse consent (at least where an advance refusal expressly authorises) to treatment or procedure necessary to sustain life

56. Conversely, there is no obvious statutory obligation on a donee (or anyone else) under MIB to seek/provide life saving treatment on behalf of an incapacitated donor or on any person to take such steps in respect of a person lacking capacity who is not a donor.

57. Nor, as I read the combination of clauses 6-7 may action be taken to avert a substantial risk of significant harm to a donor (see clause 6(1)) in circumstances where the donee/deputy objects (see clause 6(2)) and where the limitation in clause 6(3) (temporary life sustaining treatment or act to prevent serious deterioration in condition whilst Court Order sought) does not apply. It is not immediately obvious that the concept of "substantial risk of significant harm" in clause 6(1) is synonymous with the limitation in clause 6(3) even were the person seeking so to act about to seek a Court Order. So, it is distinctly possible that MIB precludes acts (if contrary to a donee's directions) which are reasonably believed to be necessary to avert a substantial risk of significant harm to the donor but which do not threaten immediate death or immediate serious deterioration in condition. In such circumstances, even if failure to act could constitute a potential threat to life the donee could prevent the act from being undertaken. In any event, it would be necessary for the person seeking to benefit the incapacitated person to seek a Court Order to be empowered to do anything to "trump" the donee's wishes. Even then, such person may not (see clause 40) have an immediate right of access to a Court but might have to seek the Court's permission to act at all.

58. In making decisions a donee is, generally, bound by MIB clause 4. But the difficulty here is, of course, (and it applies generally to any person exercising general authority under clause 6) that the assumed past and present wishes and feelings of the donor or others (see clause 4(2)(c) and 4(2)(d)) as to what may be in the donor's best interests may be very much contrary to the donor's true best interests: such persons may, for example, be temporarily suicidal or influenced by factors which have little to do with his or her general welfare. Similarly, they are only factors to be taken into account. But, the donee (and any other person exercising general authority) has a general discretion to override those views: in particular all that the donee has to show if called upon is that he reasonably believed that what he was consenting to or refusing was in the donor's best interests. It is unclear why the donee of lasting powers of attorney is given greater licence to act contrary to P's best interests than other persons exercising general authority where it must, at least, be shown that the action taken is reasonable.

59. Having regard to clause 4 two things are clear. First, the statutory criteria are an attempt to put the donor in the position of a person with capacity. But there is no true analogue because a person with capacity may often act autonomously but contrary to his or her best interests. This attempt at substituted capacity reflects an internal contradiction in the logic of best interests. Secondly, the legal threshold at which a donee is empowered to make life or death decisions on behalf of the donor is opaque, subject to potential abuse and not subject to effective control by the Court prior to the action being taken.

60. Given (see *M&H* above) the fact that "best interests" is integral to the positive obligation on the State intrinsic to Article 2 to preserve life and given, also, that this concept is also integral to the negative obligations contained in Article 2 there are several vices in MIB. There are few safeguards to prevent a donee acting in a way that is truly antithetical to a clinical judgment of where a patient's best interests lie. The presumed wishes of a person (even their actual wishes) have only a tangential connection with what is in their best interests. To equate the two is to confuse best interests and autonomy. To allow a donee to make discontinuance of treatment decisions without even having, on an objective basis, to achieve the best interests objective at all is ostensibly in direct conflict with the requirements of Article 2 as enunciated in *M&H*. Finally, there is no obvious statutory control so as to ensure compliance with the positive obligations in Article 2.

61. These deficiencies are both systemic and procedural. The procedural deficiencies are where Article 6 ECHR engages. The right of access to a Court under clause 40 is, in my view, inadequate to comply with the need for immediate access to a Court, without impediment, to safeguard the interests of incapacitated persons in an area of considerable moral and ethical controversy which may, in many instances, be at variance with objective clinical judgment.

62. Article 2 rights and the obligations inherent in domestic criminal law are plainly "civil rights and obligations" within the ambit of Article 2. Yet, the only persons who have (material) automatic access to a Court (that is, without needing permission) are the donee of lasting powers of attorney or the person lacking (or alleged to be lacking) capacity: see clause 40(1). But it is, in this context at least, the danger of exploitation and insufficient protection by the donee (and the concomitant vulnerability of the donor) that may make it essential for the donor's civil rights and obligations to be reviewed by the Court.

63. There is no obvious mechanism for the Court to become involved. Certainly, the Court can become involved and probably (but not inevitably) would if application were made to it. But there is no mechanism for the Court to become involved at all. There is no compulsion on a donee to bring the matter before the Court at all. This is, to my mind, a serious omission in Article 6 protection in this area of the law given the

substantial and effective protection that are considered to be fundamental to ECHR protection. It is also, to say the least, a temporary impediment to access (and, therefore, also a breach of Article 6) for obviously interested parties (such as those exercising general authority under clause 6) to require the leave of the Court under clause 40(2) and for there to be a general prohibition against applications without leave under clause 40. *A fortiori* given the fact that there is no statutory mechanism for the involvement of the Court at all.

ADVANCE DECISIONS TO REFUSE TREATMENT

64. It is, undoubtedly, the case that a person of adult age may make (if he/she has the requisite legal capacity) decisions to refuse life saving treatment even if that decision is irrational or contrary to that person's best interests: of the many cases see, eg, *Re T* [1992] 1 W.L.R. 782. This is because, at least in general terms, the principle of autonomy or self-determination (provided that it does not affect the rights of other persons) "trumps" that of protecting a person with capacity from acting contrary to their best interests.

65. So it is that it has sometimes been thought to be merely a reflection of the autonomy principle for a person to make a "living will" or an "advance directive" or (in the language of MIB) an advance decision to refuse treatment: in other words, to make future provision for refusing life saving treatment at a time when they no longer possess capacity.

66. The difficulty with the concept of advance refusal as addressed in MIB is that there are no obvious safeguards for ensuring that the autonomy principle is being safeguarded or the best interests principle eroded. Put more concretely, it is essential, for protecting Article 2 rights, to ensure that a person who has made an advance decision to refuse treatment possessed the requisite autonomy at the time of making the refusal and has not changed his or her mind since.

67. If those elementary matters are not required to be carefully established prior to the enforcement of an advance decision to refuse treatment there will be a necessary violation of the positive and negative obligations inherent in Article 2 because the true "best interests" of the patient will never fall for consideration, it being assumed that the advance refusal reflects an expression of autonomy.

68. To my mind the following deficiencies appear from the above-mentioned provisions of MIB:

- (a) where are no formal requirements for establishing advance refusals. Nor is there a system of registration comparable to that created for lasting powers of attorney,
- (b) The Court has power to examine the validity of an advance refusal. But there is no mechanism for challenge or obvious standing under clause 40 without the need, at least generally, for the Court's leave to make the application.
- (c) In such circumstances it may be difficult, in the extreme, for an advance refusal to be the subject of successful challenge many years after it had been made.
- (d) There are obvious dangers of exploitation of a vulnerable person who may be coerced into making an advance decision to refuse treatment. Further, the evidence needed to establish such advance refusal may often be dependent upon the oral testimony of those with a vested interest in contending that there has been such advance refusal. Advance refusal (see above) has considerable legal effect in that liability is imposed for not implementing it where there are reasonable grounds for believing that it applies to the circumstances of the case (clause 25(2)). Further (clause 25(3)) no liability is imposed for implementing an advance refusal where it is reasonably believed to apply. So, a life or death decision may be made on the grounds of a document many years old which on the most tenuous evidence is reasonably believed to apply.
- (e) Nothing in MIB implies, still less compels, any particular investigation of the circumstances of an advance decision to refuse treatment even though circumstances may have changed over the intervening years, another (but concealed) document made revoking the first or the fact of having made the advance refusal forgotten.

69. The above represent, in my opinion, deficiencies in an area where protection of incapacitated persons lies at the heart of the right to life under Article 2. The dangers of the proposed statutory regime for implementing advance decisions of refusal of consent to treatment contains no mechanism whatever for ensuring that the positive obligation in Article 2 protection are complied with, namely (see above) the obligation on the State to give life-sustaining treatment in circumstances where, according to responsible medical opinion, such treatment is in the best interests of the patient. An advance refusal will, under the MIB regime, remove this obligation because it will be seen as an expression of autonomy that, in some fashion, immunises the State from having to consider best interests at all.

70. In my opinion MIB fails, in the area of advance refusal, to legislate so as to protect incapacitated persons from having life saving treatment undertaken in their best interests as Article 2 requires (even on domestic case-law). It fails to do so because it legislates on a flawed premise—the premise being that the most shaky evidence for an advance decision to refuse treatment no matter when alleged to have been made and without the need to establish the specific circumstances in which it was made. Is, in practice, presumed to be a valid expression of autonomy for all time. In my view this is a breach not merely of Article 2 but also of the due process safeguards contained in Article 6. There is, in most circumstances, no "right of access"

to the Court for determination of validity of an advance refusal (see clause 40). On the other hand there is potential civil liability for (at least in general terms) not responding positively to perhaps potentially weak evidence suggesting the existence of an advance decision and, at the same time, an immunity from liability for responding positively to such evidence.

71. In Convention terms this is, I consider and advise, a difficult position for the legislature to adopt.

THE POSITION UNDER ARTICLE 3 ECHR

72. Article 3 ECHR provides as follows:

“No one shall be subjected to torture or to inhuman or degrading treatment and punishment.”

73. This is, like Article 2, an absolute Convention obligation. Here, we are not concerned with either torture or punishment. The question is whether, taken alone or in conjunction with Article 6, MIB causes or permits the possibility of inhuman or degrading medical treatment.

74. The concern in respect of Article 3 ECHR is, perhaps, merely a different way of formulating the Article 2 and 6 concerns (above). The obvious scope for treating vulnerable persons contrary to their best interests in MIB and in a way which deprives them of life is considerable. This arises both as a matter of structure and also in terms of the absence of adequate procedural protection. I doubt, though, if the Article 3 concerns on this score add much to the analysis set out above.

ADDITIONAL CONVENTION CONCERN

75. A particular concern arises in respect of clauses 7 and 10. These prevent, amongst other things (and subject to qualification), “the use or threat of force to secure the doing of an act which Presists” (underlining added).

76. P is, by definition, the person lacking capacity. But, of course, the entire rationale for decision-making by a person without capacity is that such person is incapable of making an informed decision for himself or herself.

77. So, if that is right, it must follow that a person lacking capacity is legally incapable of resisting in a meaningful sense. In Convention terms this means that a discrimination is necessarily embedded into MIB, namely as between those patients lacking capacity who, nonetheless, articulate resistance on the one hand and those, on the other, who may be incapable of communicating resistance (perhaps because of paralysis or other disability) or who simply do not resist. This represents, on the face of it, a permitted intrusion of privacy in the case of one type of incapacitated person which is denied to another type of incapacitated person contrary to Article 8 ECHR. There is no obvious objective justification for this differential treatment.

PT 5: CONCLUSIONS

78. My primary conclusions are as follows:

- (a) MIB is incompatible with Article 2 taken in conjunction with Article 6 ECHR because it fails to comply with the State’s obligations under Article 2 to provide practical and effective protection of the right to life.
- (b) In particular, the concept of “best interests” in MIB is defined by reference to criteria that are, at least primarily, relevant to autonomy as opposed to best interests. The decision-making powers of the donee of the lasting powers of attorney are made by reference to such criteria but leaving an area of judgment to the donee that is neither statutorily defined nor protected by access to the Court within the meaning of Article 6. Similar concerns arise in respect of exercise of the general authority.
- (c) The machinery of recognition and implementation of advance decisions to refuse treatment are similarly contrary to Article 2 because they provide wholly inadequate protection for safeguarding the best interests of persons entitled to protection under Article 2 at the time that life saving medical treatment falls to be considered.
- (d) There are also concerns, under Article 3, in respect of the matters itemised under Article 2 (above). But these concerns do not add to the analysis.
- (e) Article 14, protecting as it does against discrimination in the enjoyment of Convention rights, appears to discriminate against those incapacitated persons who can communicate objection to certain proposed conduct (see clauses 7 and 10) and those who cannot. Such discrimination is neither logical nor (therefore) objectively justified under Article 14.

79. I shall be happy to assist further if and when required.

Richard Gordon QC

August 2003

117. Memorandum from the General Medical Council (MIB 949)

SUMMARY

- The GMC supports the general aims and key principles.
- Some proposals need clarification and some important issues are not covered. So it's difficult to assess the overall effectiveness and practicability.
- Guidance on the practicalities of assessing capacity should accompany the Bill.
- Clarity is needed on who can make decisions for people aged 16 and less than 18 years. Can their decision be overruled by someone with parental responsibility?
- Under the general authority to act reasonably, for healthcare decisions, can a doctor proceed if a carer without Lasting Power of Attorney (LPA) disagrees with the proposed course of action?
- There should be restrictions on the type of medical procedures/treatments which could be authorised under the general authority and the LPA. For example contraceptive sterilisation. These might be set out in Regulations.
- Reservations about the exception to the rule against the use or threat of force or restrictions on the movements of an incapacitated person.
- Where LPAs give power to make decisions about life-sustaining treatments, they should set out the circumstances in which the donee could exercise such authority.
- It should be clear whether decisions about withdrawing life support from patients in a permanent vegetative state (PVS), or withholding or withdrawing artificial nutrition and hydration from patients nearing the end of their life, should be referred to court for a ruling.
- There should be legal protection for those who make healthcare decisions in good faith, in the belief that a valid LPA existed or that the person lacked capacity to make their own decision.
- Where an adult is incapacitated and has not previously made a LPA, it should be possible for a relative or other carer to be appointed a deputy for healthcare decisions with similar powers to those which might have been granted under a LPA.
- Advance decisions about refusal of treatment should specify the circumstances in which the refusal would apply as well as the particular treatment(s). Should advance refusals be held by the Public Guardian along with any LPA?
- More clarity is needed on the power of Medical Visitors to access confidential medical records and make reports.
- The Bill should also make clear whether participation in medical research can be authorised under the general authority of LPA.
- Key issues to be covered in accompanying Regulations or Codes of Practice should be outlined with the Bill. Suggestions for areas to be covered include: explaining how the role of Medical Visitor will work in practice; encouraging processes for local informal dispute resolution.

1. The GMC is the statutory regulatory body for the medical profession in the UK. Our core role is to protect the public by maintaining a register of doctors who are competent and fit to practise medicine. We do this by:

- Setting standards of good medical practice which reflect what society and the profession expects of doctors.
- Assuring the quality of basic medical education in the UK and co-ordinating all stages of medical education.
- Setting and administering fair systems for entry to and retention on the medical register.
- Dealing firmly and fairly with doctors whose fitness to practise is questioned.

2. We have an interest in the proposals in the Bill and accompanying explanatory memorandum, as they have implications for doctors' ability to meet the standards of conduct and care expected of doctors in their day-to-day relationships with patients and their carers. Copies of our principal guidance booklets, setting out these good practice standards, are enclosed for information:

- Good Medical Practice, 2001 edition.
- Seeking Patients' Consent: the ethical considerations, 1998.
- Confidentiality: Protecting and Providing Information, 2000 edition.

Q1 Adequacy of consultation preceding the draft Bill?

3. We participated in a consultative forum set up by the Lord Chancellor's Department. The forum had only limited information about the likely content of the draft Bill. Some key aspects were not made known to us before publication, for example the limited restrictions on the scope of powers under the general authority and lasting power of attorney (LPA). Some healthcare issues, which we suggested should be covered in the Bill, or proposed Code(s) of Practice, have not yet been addressed. This is unfortunate since, for healthcare decisions, creating LPAs will be a major new development with significant implications for doctors, patients and their carers.

Q2 Clarity of aims and objectives?

4. We support the general aims of the draft Bill, to improve and clarify the decision-making process for people aged 16 and over when they are unable to make decisions for themselves. We agree with the key principles, focusing on a person's decision-making capacity and making judgements based on their best interests.

Q3 Are the objectives adequately met?

5. In our view, the detailed proposals only go part of the way towards clarifying the legal position in relation to healthcare decisions, and may not provide adequate protection for vulnerable adults. We have concerns about how some of the decision-making mechanisms in the draft Bill might work in practice. And we believe there are important omissions, which should be covered in the Bill, accompanying Regulations or Code(s) of Practice. These points are expanded on in the comments below.

Q4 Are the proposals workable and sufficient?

6. It is difficult to assess this, without the further information sought in our comments on the Clauses of the draft Bill.

CLAUSES 2-3: PERSONS WHO LACK CAPACITY

7. The principles set out in these clauses are well established in current medical practice and reflected in the standards we set for doctors. To ensure they can be followed, it's particularly important to provide clear guidance on how to approach assessments of capacity and who should carry out this role. For example, a "prescribed person" must sign a statement about the capacity of the person granting a LPA, but there is nothing to indicate who might fill this role. This might be addressed in a Code of Practice, published with the draft Bill so that some consensus on good practice can be established at the same time. The Code might draw on current joint guidance from the BMA and Law Society which is well regarded.

CLAUSE 5: ADULTS AND YOUNG PEOPLE

8. For people aged 16 and under 18 years old, paragraph 32 of the EM warns that there is overlap between the draft Bill and other areas of law affecting their decision-making rights (eg Children Act 1989). However it does not explain how these laws might interact. In addition, there is no discussion of what effect (if any) provisions in the draft Bill would have on the current position where, for someone in this age group, a competently made refusal of treatment can be overridden by a person with parental responsibility or the court. In the absence of clarification on these points, doctors and others would be left with greater uncertainty about who can legitimately make decisions for this group of people.

CLAUSES 6-7: GENERAL AUTHORITY AND RESTRICTIONS

9. It will be helpful to healthcare practitioners, patients and their carers, to have clear legal authority to make welfare decisions on behalf of an incapacitated adult. However, we see two major concerns with the current proposal for the new general authority to act reasonably.

10. Someone relying on the general authority is expected to consult others, where practicable and appropriate, about whether a proposed course of action is in the best interests of the incapacitated person. For healthcare decisions, we need to clarify what should happen if anyone consulted disagrees, but that person does not hold any formal decision-making power (LPA or court appointment). Would a doctor be able to proceed with treatment, at least until someone with a welfare LPA or a court appointed deputy raised objections, or a court ruling was made?

11. There are no restrictions on the type of healthcare decisions which might be made under the general authority. This is except for matters regulated by the Human Fertilisation and Embryology Act, Organ Transplant Act and Mental Health Act (see Clauses 26-28). It's not obvious why these exclusions are proposed. But some other controversial treatments/procedures are not excluded so that, as it stands, the

scope of the general authority would offer less protection to vulnerable adults than under current law. At present non-therapeutic or controversial medical interventions, such as contraceptive sterilisation and withdrawal of life support from patients in a permanent vegetative state, should be referred to court for a ruling. If it is the intention that issues of this kind should no longer go to court, this should be made clear so that the impact of such a change can be debated.

12. In our experience, those involved in providing care to an incapacitated adult want clarity not only about who has authority to make particular decisions, but also about the circumstances in which it is preferable or necessary to seek a view from the court. It's our view that the draft Bill should include provision for certain procedures, to be set out from time to time in Regulations, to be excluded from the scope of the general authority and LPAs, and to require court approval. Initial proposals for Regulations should accompany the Bill. This approach would be similar to that in current mental health legislation, and in the Adults with Incapacity (Scotland) Act 2000.

13. We also comment on issues raised by the use, or threat, of force (Clause 7) in the section on LPAs at paragraphs 16-17.

CLAUSE 8: LASTING POWER OF ATTORNEY (LPA)

14. No explanation is offered why 18 is the minimum age at which someone can grant a LPA, when the provisions of the draft Bill are intended to apply to those aged 16 and over. We would expect capacity rather than age to be the deciding factor in making a valid LPA. Then it would be open to a parent (or other party) to challenge the validity of the LPA, or the acceptability of a particular donee, through the registration process.

15. Perhaps a difficulty arises from the present position where, although we generally treat the wishes of a person of 16+ who has capacity to decide in the same way as an adult, those wishes could be overruled by someone with parental responsibility or the court. If it is proposed that this situation should continue (in contrast to the position in Scotland), then it will be necessary to set out clearly how decisions should be made for people in this age group.

CLAUSE 10: SCOPE OF PERSONAL WELFARE LPA

16. We support the general principle that LPAs (and the general authority) cannot authorise the use or threat of force, or restrictions on freedom of movement, where an incapacitated person is resisting doing or having something done to them.

17. However, we have strong reservations about the exception to this general rule 1 where there is a "substantial risk of significant harm" to the incapacitated person. We consider that the use of force or restrictions on movement might be permitted only in an emergency (similar to the Scottish Incapacity Act), where it is immediately necessary to save the person's life or prevent significant deterioration in the person's health. It should not be permitted over the longer term, or in non-emergencies, unless authorised by the court. We do not see how the threat of force could be justified. Would it not leave doctors and other carers open to criminal charges of ill treatment (Clause 31)?

18. In subsection 10 (4) (b), it's clear that LPAs can make express provision for the donee to make decisions to refuse life-sustaining treatments. Given the sensitivities and the often contentious nature of such decisions, we believe that in granting such authority the donor should be required to outline the type of treatment(s) and the circumstances in which the donee would exercise authority to decide. This would be similar to, and consistent with, the elements required in making a valid advance refusal. It would also help, where both an advance refusal and a LPA relating to life-sustaining treatment existed, in resolving any doubts or conflicts over what course of action would be consistent with the wishes of the incapacitated person.

19. In our experience, producing guidance on withholding and withdrawing life-prolonging treatment, doctors and others involved in making these decisions want as much clarity as possible about what decisions may reasonably be made without referral to a court. There are two particularly contentious issues where it would be helpful if the draft Bill made clear whether they would be covered by the LPA, or in what circumstances they should be referred to the court:

- Withdrawal of life support from a patient in a Permanent Vegetative State (PVS) or near PVS.?
- Withholding or withdrawing artificial nutrition and hydration from patients nearing the end-of-life.

CLAUSE 13: PROTECTION OF DONEE AND OTHERS

20. This seems to offer protection only in relation to property and financial transactions done in good faith, where it later turns out that no valid LPA existed. Doctors and others making healthcare decisions would need similar protection.

21. In addition, a welfare LPA can only be used by the donee when the donor lacks capacity to make a particular healthcare decision. So where capacity fluctuates, decision-making presumably would alternate between the donor and donee. It can be difficult with some conditions to make a clear assessment of the person's capacity. Some protection is needed for those exercising authority under a LPA in the reasonable belief that the donee lacked capacity to make the decision for his/herself.

CLAUSES 16-17 AND 19-20: APPOINTMENT OF DEPUTIES AND SCOPE OF THEIR POWER

22. There is confusion about the role of court appointed deputies. On the face of the Bill their role seems limited to financial and property affairs. The EM states (paragraphs 67-70) they could be appointed to take welfare decisions, while suggesting that this will happen only rarely and their power will be very limited in scope and duration. In our view, the court should be able to appoint a deputy to take healthcare decisions for an incapacitated adult who has not executed a welfare LPA. Some adults will not have had the capacity to execute a LPA, and some may simply have failed to do so before becoming incapacitated. Unless it is intended that, in these cases, most of the person's healthcare would be provided under the general authority, appointing a welfare deputy would seem to be a necessity.

23. If healthcare decisions for people who have not made a welfare LPA are expected to be made under the general authority, this would seem to put these adults (and their carers) at a disadvantage. For example, some people are severely mentally incapacitated long before reaching adulthood so that many welfare decisions are made by their parents (or other carer). Their carers would expect to continue to be the principal decision-maker on their behalf, and would want this to be clearly recognised at law.

24. We would support a change to the proposals in the draft Bill so that, where an incapacitated adult has not previously executed a LPA, a relative or carer could apply to court to be appointed a deputy for welfare decisions, with similar powers to those which might be granted under a LPA. This would follow the approach taken in the Scottish Incapacity Act where the court can appoint a "guardian".

CLAUSES 23-25: ADVANCE DECISIONS TO REFUSE TREATMENT

25. We welcome the proposal to give statutory force to advance refusals of treatment, along the lines established in current case law. However, we are concerned that the descriptions given in the Bill and the EM weaken some of the current protection, by allowing a treatment to be refused without specifying the circumstances in which the refusal would apply. Currently doctors are only obliged to act on an advance refusal if it is validly made and clearly applicable to the patient's present circumstances. We support continuation of this requirement, which seems especially important where life-sustaining treatment is being refused. This would still leave scope for the circumstances to be described in broad terms only and without using scientific language.

26. We also welcome the reassurance that a person who withdraws or withholds treatment, in the reasonable belief that a valid and applicable advance refusal exists, will not be liable. However, it would put the matter beyond doubt, if it were clear whether that person would have been expected to take steps to check the position before proceeding.

CLAUSES 26-29: EXCLUDED DECISIONS

27. In addition to points raised at paragraphs 12 and 19 above, it would be helpful if the EM could set out the rationale for these particular exclusions.

CLAUSE 39: POWER TO CALL FOR REPORTS

28. Medical Visitors instructed by the court of protection are given statutory power to access confidential medical records and make a report (39(2)). There is a complementary duty to allow medical visitors access for this purpose (39(6)).

However, similar powers (and a duty to comply) have not been given to medical visitors instructed by the Public Guardian, who will be involved in the day-to-day monitoring of the use of LPAs (48(1)d,f,h). In the absence of a statutory requirement, doctors would disclose confidential records to medical visitors, only where the patient or the person holding LPA has given consent, or where they judge that disclosure would be in the public interest. (Guidance is in our booklet *Confidentiality: Protecting and Providing Information*.) This may have practical implications for the work of medical visitors.

Q5 Relevant issues not covered by the draft Bill

29. Nothing is said about whether LPAs or the general authority can be used to authorise the participation of an incapacitated person in medical research. This is an important and contentious area, which should be addressed in the Bill. We would support an approach similar to that in the Scottish Incapacity Act.

30. We would like to see specific proposals on how and where advance refusals should be recorded. This is important given that the draft Bill would create a new criminal offence of deliberately concealing or destroying an advance refusal. Would it be possible for these to be registered with the Public Guardian, alongside any LPA?

Q6 How else might the draft Bill be improved?

31. To assess the overall effectiveness of the legislation, it would be helpful to outline the key issues expected to be covered in the proposed Regulations and Codes of Practice.

32. We have two further suggestions for inclusion in a Code. Medical visitors. It is difficult to envisage how the new role of Medical Visitor, responsible for monitoring the use of welfare LPAs, will work in practice in settings such as hospitals, GP practices, care homes. Will they follow a similar approach to the system of visits under current mental health legislation, or the Scottish Incapacity Act? Without more information, it's difficult to assess how effective an arrangement this might be for protecting the interests of incapacitated adults.

33. Dispute resolution. It would be helpful if decision-makers were encouraged to use local informal processes to try to resolve a disagreement about a patient's best interests, before approaching the court for a ruling.

September 2003

118. Memorandum from Alzheimer Scotland (MIB 968)

1. INTRODUCTION

1.1 Alzheimer Scotland is Scotland's leading national voluntary organisation, which supports people with dementia and their families/carers through campaigning activities and service provision. Our membership comprises individual carers, people with dementia, professionals, provider organisations; and corporate bodies such as the Royal Colleges. We consult widely with our membership on key public policy developments and draw on the expertise of our interdisciplinary Rights and Legal Protection Committee to inform our responses in this area.

1.2 Our interest in submitting evidence is to share our experience of campaigning for the Adults with Incapacity (Scotland) Act 2000 and the emerging lessons from implementation in relation to the proposals in the draft Bill. Our campaign for legal reforms began in the mid 1980s and grew in the mid 1990s with a series of publications,¹ conferences and recommendations to the then Scottish Office. Following the publication of the Scottish Law Commission's draft Incapacity Bill in 1991, we were funded by the Chief Medical Officer to carry out a feasibility study to identify the volume and range of cases of older people with dementia that might require legal intervention, each year (key finding 16.4 per cent intractable cases with no legal solution)². In 1997 we co-ordinated the "Right to Decide" campaign for the promotion of the Adults with Incapacity Bill. Following the passage of the Act, we successfully bid (in partnership with others) for three Scottish Executive commissions: to draft Codes of Practice 2 and 6 (1999); to organise four major national training events at the launch of the Act (2001), and to monitor and research the implementation of Parts 2, 3 and 6 of the Act (to be completed by September 2004).

2. UNDERSTANDING DEMENTIA AND THE NEED FOR LEGISLATION

2.1 People with dementia are the largest group to benefit from the Adults with Incapacity (Scotland) Act 2000, which provides a comprehensive legal framework for decision-making in relation to the welfare, health and finances of people with mental incapacity. The ability of people with dementia to make decisions diminishes over time as the illness progresses and others gradually have to take over making decisions. The new legislation, in defining incapacity as decision specific, recognises the rights: of adults with incapacity to be as fully involved in decision-making as possible; of carers to be consulted by health and social work professionals; and for carers to become legally appointed proxies. People with dementia are very vulnerable to undue pressure and mistreatment, and the Act incorporates robust measures to guard against such abuse.

2.2 We believe that the Scottish Act is fundamentally sound and is proving to be successful, especially for people with dementia and their carers who represent over 50% of users of the Act.³ However, like all new legislation, the Act is not perfect. Carers and professionals have drawn our attention to specific areas in which improvements might be made to policy and practice.

2.3 It is also evident that there are sometimes misunderstandings about requirements of the Act, especially by medical practitioners, and that mistakes are being made because professionals across the disciplines are on a steep learning curve. This is indicative of the need for rigorous and extensive awareness raising and training programme. We have welcomed the commitment of the Scottish Executive to address issues arising and do not consider that they detract substantially from the achievements of the Act.

2.4 Whilst we applaud the intentions of the proposed legislation, which is long overdue, and consider that there is merit in some of its proposals, we have major concerns that it may not be “fit for purpose”, particularly in providing protection for those it is intended to benefit. The comments below relate to the specific questions asked by the scrutiny committee. Accustomed as we are to the Scottish legislation we prefer to refer to the subject of the legislation as the “adult” rather than “P”.

3. RESPONSES TO QUESTIONS

3.1 *Are the objectives of the draft Bill clear and appropriate?*

Largely yes but a clear statement that the legislation is intended to enhance the rights and protection of those with an inability to make some or all decisions for themselves in Part 1 of the Bill an explanatory note is essential to reassure service users.

3.2 *Does the draft Bill meet these objectives adequately?*

To some extent yes. In particular, the provisions for Lasting Powers of Attorney allow people to plan for future incapacity are very similar to the Continuing and Welfare Powers of Attorney in the Scottish Act. Our experience is that these are working well and are especially valued by those with an early diagnosis of dementia, because they are enabled to make advance decisions about who should make decisions on their behalf when they become less capable; and because the use of these powers will reduce the need for more invasive interventions at a later stage.

However, we consider that the “General authority to act” as expressed in the draft Bill, is not compatible with the “decision specific” concept of incapacity. It creates a tension between the objective to facilitate decision making for carers and the objective to enhance involvement in decision-making by the adult. The inclusion of Section 1, clause 2 of the Adults with Incapacity (Scotland) Act 2000 would strengthen the protection for adults with impaired capacity in the early clauses of the draft Bill:

“There shall be no intervention in the affairs of an adult unless the person responsible for authorising or effecting the intervention is satisfied that the intervention will benefit the adult and that such benefit cannot reasonably be achieved without the intervention”.

Recommendation: if the “general authority to act” is to be pursued, it should exclude the entitlement to make major decisions such as: medical, research, change of residence, the sale of a house, the management of finances over a specified amount.

3.3 *Might lessons be learnt from similar legislation already implemented in Scotland or elsewhere?*

3.3.1 We believe that the Adults with Incapacity (Scotland) Act 2000 provides a good model and note with surprise that so little reference has been made to it or the earlier Scottish Law Commissions’ recommendation, throughout the process of developing the legislation in England. That the two different but similar pieces of legislation will run on parallel lines is likely to create confusion for carers and service users, and give rise to cross-border issues, some of which are already emerging for supervisory bodies in Scotland where the appointee or adult live south of the Border. It will be especially important for the forthcoming legislation to be compatible with the Adults with Incapacity (Scotland) Act 2000 in relation to the assessment and certification of incapacity. In addition to conforming with human rights legislation, which we believe the Adults with Incapacity (Scotland) Act 2000 does, consistency will also assist issues arising in relation to banking law and the Inland Revenue where problems are already emerging.

Recommendation: to provide clarification on cross-border issues between the Adults with Incapacity (Scotland) 2000 Act and the new Mental Incapacity legislation, and cross refer where relevant.

3.3.2 The value of the five general principles on the face of the Adults with Incapacity (Scotland) Act 2000⁴ as opposed to the checklist to support the single “best interest” principle (Part 1 s4).

We note that the draft Bill has recast the over-arching principles that are on the face of the Adults with Incapacity (Scotland) Act 2000 and downgraded them to the status of a “checklist” of factors to be considered in deciding what is in an adults best interests. In the Scottish Act, the agreed principles are enshrined in law and must be adhered to no matter what type of intervention is prescribed or powers authorised by the sheriff (Part 1 s1) (with the exception of the fifth principle and there is no reason why this should not also be legally binding.)

Recommendation: that the “Best Interest” principle and checklist are replaced with the principles on the face of the Adults with Incapacity (Scotland) Act 2000.

3.3.3 Problems with “General authority to act” (Part 1 s6 and 7)

The draft Bill makes it “lawful” for anybody providing care to act when it is “reasonable to believe that the person lacks capacity” in relation to the matter in question, or to act “reasonably” in an adult’s best interests. This is a fundamentally different concept from the Adults with Incapacity (Scotland) Act 2000, which is about the appointment of a representative to make decisions on behalf of an individual. We have major difficulties with the concept that anyone claiming to provide care, can have this authority over another person. The draft Bill lacks a definition of “care” and leaves the adult, particularly where he/she is living alone, vulnerable to abuse. We can foresee conflicts over who has the “higher” authority to make decisions; and over the interpretation of what is “reasonable”. For example there may be conflicts between family members; between carers/professionals; between the adult/carer/professional, as to what is in the adult’s “best interests”. The term “best interests” also has connotations of paternalism whilst the principle of “benefit of the adult” in relation to specific decisions is less likely to lead to a conflict of interests.

We also question whether financial institutions will co-operate where an individual carer is acting under a “general authority to act”, as there could be any number of such persons claiming to care for the adult. We therefore conclude that the concept and general authority to act as currently expressed in the draft Bill is fundamentally flawed.

If the Adults with Incapacity (Scotland) Act 2000, there is a “general authority” which is specific to the provision and authorisation of medical treatment by a medical practitioner, and then only after an assessment of capacity of the patient to give informed consent to treatment. The Act allows for a medical treatment plan to be drawn up which recognises that the patient may be able to give informed consent to certain treatments, but will lack the capacity to understand and consent to other necessary treatments. We believe that Part 5 of the Adults with Incapacity (Scotland) Act 2000 provides a sound basis for medical decision-making and endorses best practice, although it may be possible to achieve some improvements without jeopardising the right of the individual (see Annex 3 Submission on Scottish Executive consultation on Part 5 of the Adults with Incapacity (Scotland) Act 2000, June 2003).

3.3.4 The Scottish legislation provides formal arrangements for assessing capacity and for certifying and recording, monitoring and reviewing, assessment of capacity. It also makes provisions for the adult or anyone with an interest to challenge an assessment of incapacity. We believe such provisions are essential for compatibility under the human rights legislation.

In the draft Bill, the “general authority” allows anybody providing care to assess the capacity of the adult “in relation to the matter in question” and to act in “all the circumstances it is reasonable for the person to do the act”. Again we stress that this gives the individual a great deal of power over the adult, without the provision of checks and balances.

Recommendation: formal measures for assessing capacity similar to those in the Adults with Incapacity (Scotland) Act 2000 should be built into the proposed legislation and not left to codes of practice.

3.3.5 Adults with Incapacity (Scotland) Act 2000 has robust mechanisms for monitoring, supervision and investigation.

The draft Bill has no mechanism for monitoring or supervising the use of the general authority to act nor for investigating suspected abuse. Under the Scottish Act the Office of the Public Guardian has the following function: to register all interventions; and to monitor, supervise and investigate financial interventions. Local authorities and the Mental Welfare Commission have powers to supervise, monitor and investigate welfare interventions. Published reports from the OPG provide evidence that this system is working well. The Act has been criticised for being over zealous in a bid to reduce the risk of abuse, subjecting genuine carers to more regulation and bureaucracy than necessary. We believe that there is room, on the basis of a risk assessment, for allowing the courts and supervisory bodies wider discretion in specific circumstances.

Recommendation: inclusion of a robust system of supervision and investigation in the proposed legislation.

3.3.6 How the Adults with Incapacity (Scotland) Act 2000 meets the principle of proportionality.

The principle of proportionality is not evident in the draft Bill.

The second principle in Part 1 of the Scottish Act is that any intervention must be for the benefit of the adult and the least intervention necessary of the achievement of that benefit, which cannot be met in any other way. This “least restrictive” principle is a fundamental test of whether the rights of the adult are observed. It means that the legislation must provide a range of measures that allow for varying degrees of intervention, tailored to the needs of the individual. How the Act can operate in this way is illustrated by the following examples:

- (a) Welfare powers of attorney are only valid whilst the person lacks capacity to carry out a specific decision, this takes account of fluctuating capacity.

- (b) Financial, welfare or joint guardianship powers applied for and granted must take account of the general principles and be tailored to meet the needs of an individual now and in the foreseeable future. There is a statutory period for review, which can be flexible depending on circumstances, eg shorter if the person has an acquired head injury and is expected to recover; longer where the person has dementia.
- (c) Range of financial interventions: where a couple have a joint “either or survivor” account, its operation by one partner can continue if the other is unable to give informed consent (previously such accounts were frozen); where a family simply needs to manage the day to day finances of the adult, an application to Intromit with funds can be made to the Office of the Public Guardian to allow the opening of a “designated” account; where a one-off decision is required for the sale of a house or signing of a tenancy agreement then an intervention order may be applied for; where financial management is complex then application for financial guardianship will be appropriate.

Recommendation: to consider how issue of proportionality is to be addressed in terms of provisions under the new legislation.

3.3.7 The Adults with Incapacity (Scotland) Act 2000 enables the appointment of a proxy or proxies for as long as required by the adult.

The financial and welfare guardianship provisions under the Adults with Incapacity (Scotland) Act 2000 were framed in a flexible way to meet the medium to long-term needs of adults with incapacity ie for those recovering from an acquired head injury to those with severe dementia; and with fluctuating capacity.

We are concerned that the emphasis on minimum intervention, in terms of the court making a one-off decision or the appointment of a deputy for as short a period as possible, will lead to multiple applications, especially where the adult’s decision-making capacity is unlikely to improve eg those with moderate/severe dementia. Legally appointed proxies need to be able to make timely decisions without recourse to the courts. We consider the appointment of a guardian or guardians, to be a more “person-centred” solution.

Recommendation: the Committee to reconsider the role of the court and role of deputy.

3.3.8 Mechanisms in Scotland for dealing with conflicts of interest before recourse to legal interventions.

The Adults with Incapacity (Scotland) Act 2000 offers an effective means of resolving conflicts where all else has failed. The key mechanism for considering whether an intervention under the Act is needed is the new Single Shared Assessment and review system introduced under the Community Care and Health (Scotland) Act 2002. Scottish local authorities report that an advantage of both Acts has been to simulate an improvement in inter-disciplinary assessment and care planning. The Explanatory Notes accompanying the Draft Bill suggest that a local Vulnerable Adults Committee might be approached to help resolve such conflicts and avoid recourse to use of the court. This may serve only to undermine rather than strengthen the inter-disciplinary assessment process.

Recommendation: to strengthen the inter-agency case review process, including the position of the carer and service user (with the support of an independent advocate where necessary).

4. GAPS IN THE DRAFT BILL

4.1 Appeal provision for the adult or anyone with an interest in supporting the adult.

4.2 General authority to treat see paragraph 3.3.3 of this submission and Part 5 of the Scottish Act.

4.3 Authority for Research⁵ (see Part 5 of the Adults with Incapacity (Scotland) Act 2000).

4.4 Advocacy. The lack of reference to the role of non-legal advocates on the face of the Scottish Act has led to confusion, particularly amongst sheriffs. People with dementia often need someone who knows them well to act as an advocate to help support them in communicating their views and wishes. But some Sheriffs have refused to admit or to hear non-legal advocates and have insisted on the appointment of a court appointed “safeguarder” or curator, who will not know the adult and is unlikely to have the appropriate communication skills (each appointment costs the public purse about £1,000). We are pleased that the right of access to an independent advocate has been included on the face of the new Mental Health (Care and Treatment) (Scotland) Act 2003, but are concerned that adults with incapacity may receive lower priority.

4.5 Legal Aid. The implications for Legal Aid are not discussed in the draft Bill or Explanatory Notes. The lack of automatic entitlement to legal aid by private individuals (other than the adult) seeking to making application for welfare guardianship under the Incapacity (Scotland) Act 2000, has been a great concern to carers who have been shocked to find that they have to pay legal costs to ensure that the needs of the person they care for are properly met. The fear of legal costs may deter applications and thus creating a barrier to access to justice for some vulnerable adults.

Recommendation: inclusion of Advocacy on the face of the Mental Incapacity Bill.

4.6 Lack of proper legal framework for management of residents' funds by care homes, hospitals (see pt 4 of Adults with Incapacity (Scotland) Act⁷ to be implemented on 1 October 2003.

5. OTHER MATTERS

5.1 Proposed title of the Act. Recommendation: removal of the word "Mental" and change to either: Capacity Act or Incapacity Act.

5.2 Alzheimer Scotland welcomes the proposal for a new Court of Protection, which will develop a body of expertise and be more user friendly. We will continue to press for a similar system in Scotland for users of the Adults with Incapacity (Scotland) Act 2000.

August 2003

Annex 1

REFERENCES

1. Scottish Action on Dementia (1988) Dementia and the Law—the Challenge Ahead.
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Scottish Office: Recommendations for the Management of Welfare and financial decisions for Incapable Adults (1996).
2. Scottish Action on Dementia & Glasgow University (1993) Feasibility Study into Mental Health Hearings for Older People with Dementia.
3. Office of the Public Guardian, Annual Report 2003 and Mental Welfare Commission unpublished statistics, 2003.
4. Adults with Incapacity (Scotland) Act 2000, Part 1 General Principles and fundamental definitions.
5. Adults with Incapacity (Scotland) Act Part 5 s51 Authority for Research.
6. Mental Health (Care and Treatment) (Scotland) Act 2003 Chapter 2, s259-261.
7. Adults with Incapacity Act Part 4, Management of Residents' Finances.

Annex 2

ALZHEIMER SCOTLAND—ACTION ON DEMENTIA

Response to Scottish Executive's consultation on Adults with Incapacity (Scotland) Act 2000

PART 5: MEDICAL TREATMENT AND RESEARCH

1. INTRODUCTION

Alzheimer Scotland is Scotland's leading national charity that aims to represent the interests of people with dementia and their carers. Dementia is an umbrella term for a number of complex degenerative neurological conditions of which Alzheimer's disease and vascular dementia are the most common. It means that whilst people with dementia in the early stages of the illness are able to maintain control of their lives, over time the ability to manage finances and make welfare and medical decisions is lost and others need to gradually take on the task of making decisions for them. People with dementia are the largest group (currently an estimated 61,000) most likely to benefit from the Adults with Incapacity (Scotland) Act 2000 and Alzheimer Scotland is committed to ensuring that the Act is implemented as intended. We therefore welcome the opportunity to respond to this consultation paper.

We have consulted widely within our membership including branches, carers groups, and our two interdisciplinary expert committees, the NHS and Community Care Committee and Rights and Legal Protection Committee. We placed our briefing and consultation questionnaire on the Alzheimer Scotland—Action on Dementia Website. Altogether 40 responses have been received and these have helped to inform our submission.

2. GENERAL COMMENTS

2.1 The Act enhances the rights of very vulnerable people in a number of ways. These include reducing the risk that they are disadvantaged because of their incapacities in receiving appropriate care and fair treatment. We consider that general medical practitioners have an extremely important role in the course of treating people with dementia, mental illness and those with other disabilities that come under the Act. It is therefore disappointing that some feel unable to embrace their new responsibilities. The needs of people with dementia and other people with diminished capacity have been undervalued for years and the Act helps to address this. The Act enhances the status of carers and aims to empower adults with incapacity. It is consistent with the broader policy intention of the Scottish Executive for patient involvement and the recognition of carers as partners in care. This requires a considerable cultural shift for many members of the medical profession; it may be that some of the opposition to Part 5 arises from a fearfulness about authority being given to others in the area of decision-making.

2.2 Alzheimer Scotland recognises that the effective implementation of the Act does have significant workload implications for all the professionals who have duties under the Act. However, the Act, which exists to protect the most vulnerable, should not be compromised to resolve what we perceive to be issues concerned with information, training and the establishment of efficient administrative systems. There was no proper assessment of the training needs of the medical profession prior to the introduction of the Act and training opportunities were limited. Training issues should be addressed with some urgency, as we believe this will make a significant contribution to the resolution of the work management problems recourse to changes in the Act.

Where changes to the Act will benefit both the adult and the doctor they should of course be considered and this response identifies where such improvements may be possible.

3. COMMENTS ON THE CONSULTATION PROCESS

3.1 We would like to register our concerns about the nature of the consultation exercise. Firstly, because consultation and research into Part 5 is being conducted in isolation from the research on the implementation of the rest of the Act. This has major disadvantages as the Act was welcomed for its integrated and holistic approach to decision making. In addition, the focus on Part 5 in this consultation is limited to its interaction with the medical profession and risks reinforcing a narrow view of the Act.

3.2 We consider that consulting after only nine months of implementation is premature, it would have been preferable for the Scottish Executive stick to the original plan to consult after the twelve month period of operation—a more reasonable test. However, we understand that the consultation was brought forward in response to pressure from the BMA and some doctors who were refusing to comply with the Act. Refusal to comply is continuing in many practices despite the consultation. A possible consequence is that some people with early stage dementia may not be advised of measures, such as the appointment of a welfare power of attorney with medical decision making powers, that would aid decision-making at a later stage.

3.3 We are concerned that the consultation does not represent an independent review, but reflects only the issues raised by one section of the medical profession and may therefore be considered unbalanced. It is framed almost entirely on the basis of the proposals advanced by the BMA.

3.4 Some of the concerns raised by the BMA in the consultation are not well informed. For example, it is misleading and inaccurate for doctors to suggest that an assessment of capacity is required every time an aspirin needs to be prescribed, and to omit any reference in the consultation paper to the Medical Treatment Plan. The Medical Treatment Plan, provided in the Code of Practice, was devised precisely to address such management concerns. The Medical Treatment Plan also respects the principles of the Act in terms of (a) involving the patient as far as possible in treatment decisions (b) minimum intervention ie avoiding the need for additional assessments.

3.5 The consultation paper fails to question the information and training needs of GPs and other doctors, and any assessment of how far these have been met. Training opportunities have been limited and it is our belief that many of the workload concerns of GPs would be addressed were they to have received timely information and training about the Act and simple guidelines about what they are expected to do. Our experience from input to postgraduate training for GPs is that the general leaflet and video are felt by GPs to be inadequate and don't provide the detailed advice they are seeking about assessing capacity.

3.6 We recommend that the remit for the research programme should include an investigation into the exact nature and extent of the issues raised by doctors.

3.7 We seek reassurance that the findings from the Part 5 research programme will be considered alongside the recommendations for improvements that may emerge in relation to the implementation of other parts of the Act, before any proposed changes might be taken forward for the Code and/or the Act. We are concerned that there is a limit to the number of times the mechanism of a miscellaneous amendments bill or regulations can be used in respect of existing legislation. We are concerned about how the responses to the consultation will be weighted and evaluated. We seek reassurance that any changes taken forward will adhere to the principles of the Act, and will be for the benefit of the adult as well as the doctor.

Our response to the specific questions for consultation is set out in the table below.

4. DETAILED RESPONSES TO CONSULTATION QUESTIONS

3.8 Proposals for change to the Part 5 Code of Practice

3.9 Point 1

Would it be possible to have a variable assessment procedure, which reflected the scope and degree of the intervention or treatment proposed? If so, suggestions on how the Code might be amended would be welcome.

3.9.1 Response

The Code already allows for this flexibility; it does not prescribe how the assessment is to be carried out, so we don't consider that an amendment to the Code is necessary. The guidance suggests that the assessment procedure will depend on the nature and complexity of the decision to be made and the extent of the incapacity of the adult. However, consultation with others closely involved with the adult's care is required where reasonable and possible. The section in the Code on the Use of Treatment Plans (2.19–2.24) is excellent and aims to reduce the assessment task where there are multiple treatments. The Code advises on the involvement of specialist therapists and others as appropriate. However extensive multidisciplinary assessment will only be needed for a minority of patients. For the majority of adults with incapacity, the general practitioner may not need to carry out an extensive assessment.

The section Taking Account of the Wishes of the Adult (paragraphs 2.27–2.31) is especially important: "The medical practitioner must take account of the past and present wishes and feelings of the adult in so far as they can be ascertained by any means of communication. This is an unqualified obligation".

3.10 There seems to be a fear that, for example, everyone with dementia in a care home will need to have their capacity assessed before they can be treated. We do not believe this to be the case. In our experience, many people are often assumed to lack capacity because of their diagnosis eg dementia, or learning disability. The Code rightly points out that incapacity must not be equated with inability to give informed consent. We know that with the use of good communication and listening skills, many people with incapacity will be able to consent to regular treatments, and particularly those with which they are familiar. Often consent will be by non-verbal communication and the Code of Practice gives helpful guidance on this. Communicating with adults with incapacity does take time but this should be a matter of normal good practice.

3.11 Point 2

The Section 47 certificate states that the examination has "to-day" been carried out, thus potentially diminishing the relevance of earlier, and possibly still valid assessments. The BMA therefore propose that "to-day examined" be dropped from the certificate and replaced by eg "based on my considered opinion . . ." This would allow still current assessments and other relevant information to inform the certification process. This could be achieved by subordinate legislation. Views are invited on this change.

3.11.1 Response

It has been suggested earlier that assessments may be considered less valid if the certificate has to state that the examination has "to-day" been carried out. There is no reason to suppose that this is the case. Such assessments might contribute to informing the doctor's judgement. Since the examination is in relation to a treatment decision, if "to-day" is removed there may be a danger of making treatment decisions without having seen the patient, possibly for some time, and of not communicating with the patient about the new treatment. However, we would not be opposed to the doctor completing a certificate that states he/she has carried out an assessment and examination within the past seven days, with "assessment" being understood to include evaluating other evidence beyond the immediate examination of the patient.

Again, this is where the Medical Treatment Plan is helpful.

3.12 Point 3

The Code of Practice states, at paragraph 2.25, that a certificate of incapacity under section 47 is needed even where a proxy exists. What are your views on this point and has this requirement had an adverse impact on services to patients?

3.12.1 Response

There may be specific circumstances where an assessment of capacity on an annual basis may not be appropriate, for example: where a proxy exists for an adult with severe dementia who is clearly not going to regain capacity to give informed consent to any treatment decisions. In such circumstances the adult may benefit from the removal of the necessity to have their capacity reassessed (ie principle of minimum intervention for the benefit of the adult).

Where the appointee is a welfare guardian with medical decision-making powers, the court will have required two medical certificates of incapacity, and the appointee will have been deemed a "suitable person." This could be considered sufficient in such circumstances.

Where an attorney has been appointed with powers to make medical decisions, a medical certificate is not required unless specified by the grantor. Whilst the attorney must abide by the principles of the Act there is a low level of protection in such circumstances. An additional safeguard might be the requirement for an

assessment of incapacity, lasting in the first instance for one year, with no further requirement for assessments of capacity thereafter. If the doctor or anyone else has misgivings about the motivation of the proxy with regard to a specific treatment decision i.e. a refusal to consent, this would be open to challenge and the dispute procedure put into operation.

The proxy has the duty to act on behalf of the patient and in accordance with the principles of the Act, and there are potential sanctions if a proxy does not act properly. In all other parts of the Act a proxy is empowered to make decisions on behalf of the Adult. The opportunities for appeal, complaint and investigation provide adequate safeguards. Therefore, with the above exceptions, we do not consider it necessary for there to be a certificate of incapacity under section 47 where there is a legally appointed proxy.

We have heard of two cases where, because the GPs concerned have refused to comply with the legislation, there has been a delay for the patient in receiving dental treatment. In each case the carer had appropriate powers of attorney and believed they had the legal authority to consent to the proposed treatment. They were very frustrated at having to return to the doctor who then required a letter from the dentist about the treatment required which added to the delay.

3.13 Point 4

Are there any other ways in which changes to the Part 5 of Code may help streamline the operation of the Act, without encroaching on the principles of the Act?

3.13.1 Response

The Code provides little advice on the establishment of an infrastructure within the areas of the NHS with responsibility for the operation of Part 5. This has given rise to a range of problems that impact on the efficient implementation of other parts of the Act as well as Part 5. Problems raised are:

- lack of a lead to provide management and overview of the system and quality assurance in acute and long-stay hospitals, for example, we have received reports of excellent information, training and implementation in one hospital ward, but a complete lack in the ward next door;
- doctors not knowing where to find certificates and not understanding the difference between them; lack of management and overview of the system in health centres and GPs' surgeries;
- certificates not accompanying patients on admission to care homes or hospital, leading to duplication of work for doctors and potentially putting the patient through further unnecessary assessments;
- lack of systems to flag up when certificates need to be renewed.

Health Boards should therefore be required to set up and resource an appropriate infrastructure to include a system for the renewal of certificates and to ensure that that appropriate certificate accompanies the patient.

The Code of Practice should make it clear that doctors cannot charge for certificates of incapacity under Part 5 of the Act.

3.14 BMA and SGPC suggestions for amendment of Part 5 of the Act

3.15 Point 5

The duration of a certificate is limited to one year. The upper limit was set when legislation was going through the Scottish Parliament and was increased from the initial period of three months. It is suggested that the upper limit should be raised from one year to three years. This would be consistent with other parts of the Act, and would be appropriate, eg where some long-term conditions were concerned, in which there was little or no prospect of capacity being regained. Views are invited on this proposal.

3.15.1 Response

There may be room for extending the time for renewing certificates of incapacity in certain circumstances with qualifications in relation to certain treatments, and that a second medical opinion should be sought in such circumstances. However to increase the upper limit from one year to three years as the norm would incur the risk that those with fluctuating capacity or who may improve might have their rights jeopardised. There was a suggestion, amongst our responses, that the upper limit should be no more than two years.

3.16 Point 6

Views are invited on whether more flexibility should be given in Part 5 of the Act to allow other health professionals, other than doctors, to sign the certificate of incapacity, including eg dentists and opticians. If so, which health professionals should be allowed to sign and why would this be appropriate in relation to incapacity to decide treatment, when all other certificates and reports under the Act require to be signed by medical practitioners.

3.16.1 Response

It is perfectly reasonable to expect that the doctor with primary responsibility for the treatment should sign the certificate, having first consulted with others as appropriate.

The Code allows for circumstances in hospitals where that doctor might not be immediately available. However, the code could be clearer on the issue.

In terms of general authority to treat, the doctor primarily responsible, usually be the GP, will have the medical treatment record, will be able to draw on what has or has not been acceptable to the patient in the past, and will have a rapport with the patient.

However, there is a case for allowing others, such as clinical psychologists and mental health nurses, with specialist training in communication skills and assessing capacity, to take a lead in certain cases and have authority to sign the certificate.

There are implications to be considered for the introduction of nurse prescribing. Designated nurses would need to be trained in assessing capacity if they are to have the authority to sign a certificate.

The issue of whether a dentist should be able to sign a certificate is not straightforward. As the Code states, the doctor does not need to understand the dental treatment proposed, but only whether the patient is capable of consenting to invasive dental treatment (more than just oral hygiene which is included in the definition of fundamental health care). Dental treatment can be included in the Medical Treatment Plan. In our responses we received a lot of opposition to the idea of the dentist assessing capacity, because the dentist is visited much less frequently and is not felt to know the patient. We have received reports of poor practice by dentists because of a lack of understanding of dementia and how to best to communicate.

We received some support for another approach, which would be for the provision of short courses on assessing capacity. Specified qualified health care professionals who have attained the certificate would then have authority to sign a certificate of incapacity. It was also considered important that the issue of assessing capacity should be a compulsory part of undergraduate and post graduate training for doctors.

If authority to sign certificates of capacity is to be extended to other health care professionals consideration will need to be given to the issue of access to other relevant information and assessments that may be held in the patient's file by the doctor. The disadvantages of having a plethora of health professionals are that: it could lead to unnecessary multiple assessments; conflicting outcomes; the lack of an integrated medical treatment plan which the doctor primarily responsible should manage; he/she would still have the job of ensuring co-ordination and consistency.

3.17 Point 7

3.17.1 The BMA proposes that the definition of medical treatment is too broad and potentially precludes the access of the incapacitated adults to routine treatment without formal assessment and certification under Section 47. Would it therefore be possible to refine the definition to exclude certain forms of treatment eg general care such as oral hygiene, nursing care, blood pressure recording, thus simplifying the assessment and certification process? If so how might this be achieved?

We are fundamentally opposed to the redefinition of medical treatment and fully support the existing legislation.

The Act and Code of Practice (2.26.2) state that "Treatment without legal authority is not an option". During the legislative process considerable attention was given to the definition of treatment and a consensus was reached only after lengthy negotiation to ensure maximum protection for the promotion of the mental and physical health of the Adult.

The Act defines fundamental health care as medical treatment, and whether the adult is able to give informed consent to this can be considered within the Medical Treatment Plan. There should be no fear of threat that the adult may be potentially precluded from accessing routine treatment because of the requirements of the Act. We therefore consider it unwise to consider reducing the scope of the definition of medical treatment. Certification simply provides evidence that good practice has been followed and should not be time consuming.

We consider that to exclude certain forms of treatment would be contrary to the human rights principles upon which the Act is based and would serve to endorse bad practice. The consequences would be to erode the rights of the adult and of any proxy. If treatment of the adult goes ahead out-with the legislation then:

- the necessity to communicate with the patient about the treatment decision is precluded;
- the protections afforded under the Act with regard to the use of restraints, whether this be the use of covert medication or the use of physical restraint to give an influenza vaccination or take the adult's blood pressure, would be significantly reduced;
- to assume incapacity for general treatments and to remove the requirement for an assessment and certificate would be to disregard the rights of appeal by the adult or by an interested party and would undermine the rights of a proxy with medical decision-making powers
- "nursing care" is too broad a concept, as is the concept of "routine" treatments, and the danger is that these could be interpreted to include the prescribing of inappropriate drug treatments such as the use of neuroleptic drugs to control challenging behaviour in people with dementia. There is considerable research evidence to show that this is happening and the Act was welcomed as a means of controlling this area of bad practice;
- there is a danger that the use of covert medication will go unchecked; and

- some “routine procedures” may not be routine for patients, who may find them frightening and refuse to co-operate, leading to the danger of recourse to the use of restraints in such circumstances.

3.18 Point 8

3.18.1 Any other points on Part 5 welcomed

Response

1. The existing code gives no guidance on the covert administration of medication where the adult lacks capacity to give informed consent to take a prescribed medicine. Research indicates that the covert use of medications is prevalent, especially in long-term care settings. There is strong evidence that tranquilisers are being used inappropriately to control challenging behaviour in people with dementia and learning difficulties. The existing Code rightly makes reference to the Mental Welfare Commission’s excellent guideline on Rights, Risks and Limits to Freedom (2002) in relation to the use of force or detention, but does not make reference to the covert use of medication for the purpose of restraint (for which the same ethical issues apply). The revised Code would benefit from the inclusion of a paragraph on this issue. We would also support regulations for the prescribing of neuroleptic drugs and to control the covert administration of medication.

2. There is concern that the Act and Code of Practice does not take account of the practical issues arising with regard to general authorisation to treat patients in acute hospital wards. The question is whether certification of incapacity is always appropriate before treatment is authorised to commence with a patient who is unable to give informed consent. Many elderly patients are admitted to acute hospital wards, and at the point of admission it is not known whether their incapacity is temporary, due to an acute illness, and/or whether they have some previously diagnosed cognitive impairment. Many elderly patients panic or are very insecure when taken into hospital and could have symptoms that imply dementia, but once settled these symptoms disappear. Whilst treatment may not be a matter of life and death, any delay to treatment might lead to serious deterioration of their health. Consideration might therefore be given to extending the definition of “emergency treatment” to cover a very short, specified, period of time after admission to acute hospital care. Thereafter normal procedures would be followed.

3. Part 5 is the only part of the Act which is mandatory, yet it is the only part which does not contain penalties for non-compliance. Whilst cases of assault could be taken up by individual patients, this is highly unlikely where adults are vulnerable and lack capacity. In addition, this does not deal with the refusal of many general medical practitioners at present to comply with the Act. This non-compliance is not only having an impact on the treatment of adults under Part 5, but also on the operation of other parts of the Act. Consideration should be given to what sanctions would be appropriate if doctors deliberately fail to comply with the legislation.

4. It is felt that some doctors have little understanding about dementia and other conditions such as adults with profound and complex learning disabilities, and that the inclusion of definitions might be helpful.

119. Memorandum from Islamic Concern (MIB 969)

1. I would like on behalf of the 1.6 million British Muslims, including 30,000 Muslim doctors and health professionals, to present to you our clear united view against any intentional ending of the life of any patient, whatever means or way, direct or indirect, active or passive, by commission or omission; but especially by depriving patients of their basic human rights to food, fluid and life-saving treatment.

2. We British Muslims would like in particular to submit to you our strong opposition to the government’s draft Mental Incapacity Bill.

3. All Muslims in Britain, Europe and all over the world believe that life is sacred and that only God, the Creator of all, is the Owner and Author of life. Only God Almighty will decide about the end of the life of each one of us. No doctor, judge, court, MP, Lord or relative can give any legitimate ruling to end the life of any patient or any innocent human being by any means or way.

4. All patients and the disabled, the old and the chronically sick are equal in the eyes of God and their life is sacred. For Muslim patients the best death is to die naturally without taking any step to end one’s life. A patient who ends his/her life “has played God”, “challenged God”.

5. This is why all types of euthanasia (whether direct or indirect, active or passive), suicide and assisted suicide are prohibited by all the Holy Scriptures.

6. For example, God (Allah) said in the final holy book Al Qur’an:

In the name of God, the Most Compassionate, the Most Merciful:

- “God/Allah takes the souls at the time of their death, and those that died during their sleep . . .” (chapter 39, verse 42).

- “And (God) is the one who gave you life, then shall he ordain you to die, then shall he give you life again, truly mankind is ungrateful . . .” (chapter 22, verse 66).
- “Do not kill yourselves, for verily Allah has been to you most merciful.” (chapter 4, verse 29).
- “. . . take not life which God/ Allah has made sacred” (chapter 6, verse 151).

7. It is also inhumane to take any step of action or omission intentionally to end the life of any patient. The provision of food and fluid is a basic human right and need for the sick and the healthy, for men and animals alike. No one has the right to stop it or withdraw it from any creature (with the intention of causing or hastening death) but we should provide it to all until the moment of natural death, as fixed by God Almighty. Otherwise one is killing the patient directly (euthanasia) and causing his/her death by starvation and dehydration.

8. Food and fluid are not to be considered medical treatment. It is ridiculous that healthy people who are having daily food and fluid could be considered to be having medical treatment.

9. Likewise, to omit a life-saving treatment is unethical, inhumane and against good medical practice.

10. It is in the best interests of patients to be given all possible means to protect their lives; care, love and counselling; family and social support; treatment for any sub-clinical depression; the best analgesic care; and to be allowed to die naturally, as God wanted according to his time, and not as the doctor, relative or court may have wanted.

11. The making of an advance decision with a suicidal intent should be illegal. Such a “living will” would be more accurately described as a “death will”. Even if the law would allow for suicidal advance decisions, they should be rejected and certainly not regarded as legally binding.

12. Any court or “lasting power of attorney” should protect the life of every patient (mentally incapacitated or not) and prohibit any means or procedure which will end the life of any patient (direct or indirect, by commission or omission), especially food, fluid, or any life-saving treatment.

13. Many mentally incapacitated patients do not give their consent to withdraw or withhold food and fluid from them.

14. Patients with or without mental incapacity have equal rights and equal obligations. Any mentally incapacitated patient should have the same protection for his/her life like any other patient, so that no exploitation of the vulnerable can occur.

August 2003

120. Memorandum from the British Association of Social Workers (BASW) (MIB 997)

BASW welcomes the publication of this Draft Bill. However, we agree with the Law society response in stating:

“that whilst we would wish to fully embrace these proposals it is not possible to understand the impact of them without first examining the code of practice which accompanies the legislation.”

We would highlight particularly the following issues and append a further submission from BASW's special interest group in this specialist area.

BASW is the largest organisation of qualified professional Social Workers, which publishes Professional Social Work on a monthly basis. We have professional officers for Scotland, England, Wales and Northern Ireland and a number of specialist groups with particular interests. BASW has produced a professional Ethical Code of Practice, which is widely accepted as definitive for Social Work practice.

1. The Best Interests principle is a legal one, and to some extent could be criticised as being subject to paternalism or indeed medical paternalism since it seems to be largely within the realm of a medic to decide. As Social Workers we are concerned that the issue of capacity and its determination is really a social determination rather than a medical one. Medics could be accused of partiality in this matter since it would appear the issue is only investigated when a Treatment (Medical) is at issue and then a medic determines whether a person lacks capacity to give consent and then arranges for someone to make decision on their behalf. At best one could argue that a different medic should make the determination on capacity to avoid the possibility of invested interests being possible.

2. Who decides what is in the “Best Interests” is clearly an issue that the Bill has given some thought to, and many groups appear to misunderstand. We believe the Bill to be saying that the substitute decision maker should not be deciding what they feel is in the Best interests of the patient, or what the doctor feels is the best interests namely the Treatment in question, but what the patient themselves would have wanted. This is a difficult concept and LPAs and deputies and the Courts need to be clear about this. Advance statements, refusals and directives are very important here and should be encouraged for all those with fluctuating or

deteriorating capacity and for those who lack capacity during acute or chronic phases of illness. This is a practice issue, which should guide both medics and social care professionals working with such patient groups.

3. Clearly there is an issue for those patients who never had capacity and how their care is managed and the role of parents who legally would have had decision-making capability during their childhood. Would Parents naturally continue to have decision-making capabilities? It seems this issue needs clarification.

4. At the age of majority it would appear that parental care decision-making is substituted by medical decision-making and the role of carers is subjugated.

5. We are concerned that there should be explicit statements that decision-making and capacity should not be confused with a lack of ability to communicate. Communication attempts should first be exhausted and those who are best able to communicate utilised as interpreters. This should include family members, carers, care professionals and not just the medics attempt via what is normally a formulaic assessment of capacity.

6. We would like to see recognition of the Social Care professional in the determination of capacity, to provide a balance against the medical model, which may highlight a need for treatment. The social care dimension would provide a check and focus on the rights of patients to refuse treatment as required by the Human Rights Act and indeed the Magna Carta.

7. We accept the view that capacity should be presumed unless there is a need to challenge that presumption. However, we do not accept that it is a medic that is the best person to decide when to challenge that presumption and/or to determine the capacity issue.

8. It would seem to BASW that capacity is a social determination, which could be best undertaken by a social care or psychological Professional rather than a medic. Capacity loss may have a physical cause but its evidence is behavioural or social in effect.

9. We would invite the committee to examine in more detail the application of the Incapacity legislation in Scotland from which we can learn many lessons.

10. We do not feel that the issue of fluctuating capacity is fully explored within the Bill what happens when people regain the ability to decide for themselves? How long does substitute decision making last and can it be re-instigated without further reference to legal determination? Perhaps social care professionals could be used as arbitrators? Rather than expensive legal options.

11. We also have grave concerns about the ethical position of a substitute decision maker especially where drug trials or research and development are concerned. How can a drug trial, which may offer no clinical benefit to a patient, be in their best interests? It may be in the interests of medical science or even other patients but we are reluctant to allow patients who lack capacity with no ability to refuse or opt out or challenge their own treatment to be subjected to either drug trials or R&D.

12. The Law Commission and the BMA have already published guidance on the assessment of capacity from a legal/medical viewpoint, we would like this guidance to include and be available to social and psychology professionals to enable the registration of professionals who may be able to undertake this very important task with appropriate training in Medical/legal and social perspectives on capacity.

13. A balance on the use of powers and an ability to protect and intervene with patients who lack capacity would be the development of a Public Law Duty to investigate and protect patients where there is suspected abuse or neglect.

14. It is suggested within the Bill that a criminal offence of "ill treatment and neglect" should be created. We are concerned that this should be extended to cover exploitation as well and should provide the ability to protect the victim as well as prosecute the perpetrator.

15. The success of the Scottish Act is due in no small part on the duties imposed on local authorities. In addition there was created a "Mental Welfare Commission", which has oversight of both the Public Guardianship Office and the Local Authority. These practical safeguards are a desirable feature, which should be incorporated into England and Wales legislation. This should also prevent a two-tier system for the protection of vulnerable adults being created in the UK.

16. We have concerns regarding the "General Authority" to make decisions, whilst recognising the need for some sensible operational system of managing day-to-day decision making without building in adequate safeguards. Especially in social care settings such as hospitals, care homes, day centres, private homes and any public place or setting where services are provided. The possibility of the misuse of the general authority powers without safeguards is therefore great.

17. We are also concerned that there is no legal definition of what constitutes "care" and whether the Bill applies to people cared for in their own home or under the care of a carer.

18. A number of Social Care organisations have expressed concern about the possible abuse of the general authority and a resolution mechanism perhaps utilising the Local authority could perhaps be incorporated to address these concerns.

19. We are concerned that clarity is provided to explain the role of different substitute decision makers where more than one may exist for example one person may have financial decision making capabilities whilst another welfare decision-making authority. Conflicts should not arise, however, some arbitration method should be established.

20. We are concerned that Local authorities as well as the Health Trusts and PGO should be informed of all LPAs in order to register them locally and ensure that LPAs are effective.

21. We are also concerned that this Bill should be financed appropriately and that means adequate resources for the Court of Protection and an expansion of the role of the PGO. Local authorities will need some extra financing to enable social care professionals to undertake the role of public protection, capacity assessment and assistance in development of advance statements for those that require them.

22. We are concerned that patients who lack capacity will be able to access legal aid for appropriate legal representation. The lack of direct provision in Scotland produces delays in legal proceedings and has reduced the effectiveness of the Incapacity legislation.

23. We are concerned that the true costs of this legislation are met by central government and that those costs may be considerable.

24. Our other concern is that the Incapacity legislation must be compatible with the new Mental Health Bill and ideally should be considered in parallel. Issues such as ECT, the role of a nominated person v an LPA etc. Must clearly be addressed within both Bills.

25. Social Care Professionals manage the care of people who either have fluctuating or deteriorating capacity as part of their normal duties. The requirement to address capacity issues as part of their Care management/care programme Approach should be routine practice. This is a development, which needs to be addressed within the legislation.

26. Finally we are concerned that this Bill has been issued without substantial work being undertaken on the associated Code of Practice. We would like to be involved in the progress of the Bill and Code since we feel that the social care perspective on capacity is essential to ensure that rights are protected.

August 2003

121. Memorandum from Marilyn Tickner (MIB 998)

The following comments and observations are based on my background in mental health services; first-hand experience in developing services for older people with special mental health needs; an M.Sc in Applied Social Studies; and an Advanced Award (AA) in Social Work. They also draw on my work in facilitating BASW's working party on mental incapacity and decision-making.

In respect of the latter, although these are my own personal comments and observations, they attempt to tie in the proposals made in the Draft Mental Incapacity Bill (2003) with the recommendations made in BASW's Position Paper on mental incapacity and decision-making in 1998 and the Association's responses to consultation papers and Green and White Papers made over the subsequent period of five years. They may or may not, therefore, reflect current social work practice in the area of mental incapacity and decision-making.

GENERAL POINTS

This Draft Bill is concise and is accompanied by explicit, business-like Explanatory Notes. Despite this, the Bill is not, in my opinion, very user friendly as the document utilises language and terms that are, at times, overly legalistic which has the effect of making the document and its provisions at times, dense and hard to read.

This very important and long-awaited piece of legislation has the potential to affect many people and improve their quality of life with its wide-ranging provisions. Therefore, I believe that the Draft mental Incapacity Bill could and indeed should be made more accessible by addressing and improving its terminology.

Unfortunately, in contrast to earlier documents on mental incapacity, this Draft Bill lacks the holistic view of someone who has reduced capacity and his or her carer.

In this respect, it is noticeable that neither the Explanatory Notes nor the Draft Bill make any commitment whatsoever to the need to maintain the rights and identity of someone who is mentally incapacitated in a manner appropriate to a multicultural, multiracial society whatever his or her age, race, gender, sexual orientation, ethnic, cultural and religious origins (Mental Incapacity and Decision-making: Professional Implications for Social Workers (1998) page 12 refers).

Instead, the Bill concentrates on the medico-legal perspective of decision-making processes with and for individuals who are mentally incapacitated for example in areas of medical treatment, and excludes the social dimension in such matters as accommodation and social care thus effectively downgrading the importance of the psychosocial aspects of mental incapacity.

Although the Draft Bill opens fairly well it becomes increasingly limited and derivative as it goes on. People, who are disadvantaged by mental incapacity, whether permanently or temporarily, seem somehow to become decentred from the locus of decision-making.

The Draft Bill's definition and criteria of mental incapacity are very positive measures, but the balance of the document is skewed towards the role of carers and the means of giving them legal protection.

Overall, therefore, the Draft Bill's proposals ensure that any changes it puts forward remain within the normative spectrum of change and will consequently maintain some of the imbalances that currently exist within the status quo.

PART 1

1. *Persons who lack capacity; and 2. Inability to make decisions*

The acceptance of the Law Commission for England and Wales' ("the Law Commission") definition of who are mentally incapacitated and attendant caveats is to be welcomed. Even so, while it lays down the criteria, the document states at a later stage that the "... court may make declarations" about whether a person has or has not capacity (1: 15 refers). The Draft Bill does not make it mandatory for the court to rule on capacity nor explains how, when, or where such a determination is to be made or whether it should be formal or informal—by a judicial authority after multidisciplinary assessment?

BASW has maintained throughout that everyone with reduced capacity has the right to multi-disciplinary and multi-agency assessment (see 1.3(2) below).

In the interest of equal opportunity etc, it is vitally important to ensure that we only arrive at the point of deciding that someone is mentally incapacitated after those procedures and processes have been gone through in a transparent manner. This is also a crucial practice issue that needs to be dealt with in an accompanying Code of Practice.

3. (2): *Presumption against lack of capacity*

This provision is worrying. I can envisage it being used to contradict and/or undermine the provisions of 3(1) in the Draft Bill. BASW's long experience in this area suggests that it will inevitably be perceived by some, as the means to declare that a person is mentally incapacitated on the basis of previous behaviour without having gone through the courts and/or undergone a multidisciplinary assessment. It may also lead to someone whose mental incapacity is of a temporary and/or intermittent nature to be regarded as permanently of reduced capacity.

BASW has repeatedly stated that people with reduced capacity have a right to multi-disciplinary and multi-agency assessment of their condition (Mental Incapacity and Decision-making: Professional Implications for Social Workers (1998) page 12 refers); BASW Response to the Green Paper on Mental Incapacity and Decision-making: Who Decides Making Decisions on Behalf of Mentally Incapacitated Adults page 10 refers); BASW Response to the White Paper: Making Decisions: Release of Payments Scheme page 13 refers).

4. *Best interests*

BASW endorses the use of "best interests" in relation to people with a reduced capacity. Unfortunately the standard of "best interests" is often glibly bandied about and too thoughtlessly applied by busy staff, perhaps untrained in the social dimensions of decision-making and preoccupied by the need for defensive practice. The result is that the medico-legal model often dominates decision-making processes with someone who is mentally incapacitated.

Although much of 4(1) and 4(2) are good practice, which BASW agrees with, they are far too limited. There are loopholes here too, such as "4(2(d)) '... if it is practicable and appropriate to consult them ...'". To be sure, under-resourced, poorly trained staff will bypass these provisions when under pressure and/or given little organisational support.

Moreover, where are the references and commitment to advocacy for individuals who are mentally incapacitated that we saw in earlier papers on mental incapacity, such as the Mental Incapacity Report (1995)? BASW has repeatedly voiced its commitment to the availability of advocacy for people who are mentally incapacitated and their carers ((Mental Incapacity and Decision-making: Professional Implications for Social Workers (1998) page 12 refers). I think that BASW should again remind the Department of Constitutional Affairs (DoCA) that advocates have an important role to play with and for this group of people.

This part of the Draft needs to be considerably strengthened as a whole to add a more positive social dimension to decision-making. The inclusion of advocacy, multicultural and multiracial issues etc would be a start. I would also like to see more of the provisions made in the Explanatory Notes included in the Bill itself, for example a statutory requirement to ensure that all methods of communication are fully explored and utilised vis-à-vis individuals who have problems with communication. This should be up front, not tucked away in the Explanatory Notes that may or may not be read. These factors need to be incorporated, if only to comply with issues under ECHR.

In the past, BASW has also called for greater use of “substituted decision-making” in decision-making processes for this group of people and, although it is not perfect, the Association has developed a Charter of Rights and Social Needs that attempts to operationalise the issue (Mental Incapacity: Professional Implications for Social Workers (1998) page 12 refers).

As this standard of decision-making requires more time and entails some degree of risk-taking, however, it will need to be accompanied by a qualitative change in mindsets together with different modes of training, organisational attitudes and criteria relating to the “duty of care” concerning vulnerable individuals. This Draft Bill provides the opportunity to build it into legislation. It can be done; it just requires the will, the wit and more resources.

5. *Adults and young people*

BASW has previously called attention to inconsistencies in current legislation whereby young people aged 18 are regarded as within the ambit of adult legislation and those under 16 are seen as the responsibly of child care legislation (BASW Response to the Green Paper on Mental Incapacity and Decision-making: Who Decides? Making Decisions on Behalf of Mentally Incapacitated Adults page 7 refers).

Again, this proposal made in the Draft Bill is to be welcomed as it will bring clarity to a confused area of practice and will provide continuity of care between children and adults.

6. *The general authority; and 7. Restrictions on the general authority*

BASW agrees with the restriction on the general authority to constrain a person’s liberty of movement unless life and limb are threatened and BASW has previously drawn attention to the need to legislate in this area (Mental Incapacity and Decision-making: Professional Implications for Social Workers (1998) page 13 refers).

Otherwise, this part of the Bill seems narrow and materialistic in scope with a decided medical orientation. But given that “best interests” is also restricted in its conception then perhaps it’s inevitable that the general authority will reflect those perspectives and exclude the social dimension. By expanding “best interests” it should be possible, hopefully, to expand this section. The entire section on general authority needs to be broadened to encompass social aspects of decision-making and advocacy in relation to people whose capacity is reduced. For example, what about the process of deciding mental capacity? As no one person is meant to hold general authority and a donee or Deputy can overrule any decision made under General Authority, who takes the lead when this or any decisions are required and who and/or what are the means of resolving conflict say between carers and/or donees?

When such conflicts occur who represents the person who is mentally incapacitated and how are the interests of the person whose capacity is reduced going to be protected within this general authority? How do advocates fit in here, if at all?

The underlying issue here seems to be the role of caring (see above 1.4: Best Interests). Although the vast majority of those caring for people with a reduced capacity are honest and genuine in their commitment to the person they are caring for, BASW has always been aware that mentally incapacitated adults are often highly susceptible to abuse and exploitation.

Mindful of this and the amorphous nature of carers as a group and the ubiquitous everyday decisions they make for and on behalf of vulnerable individuals, BASW has consistently raised the issue of who and/or what defines the nature of caring (BASW Response to the Green Paper: Making Decisions on Behalf of Mentally Incapacitated Adults (1998) pages 14–15 refer); and BASW Response to the White Paper: Making Decisions Release of Payments Scheme (2000) pages 15–16 refer).

While recognising that there can be no guarantees, decision-making under the General Authority proposed in this Draft Bill does not seem to offer enough safeguards, in my opinion, to eliminate the possibility of abuse and exploitation in regard to vulnerable individuals. Is there a case for a charter of rights to be enshrined in this Bill, such as that put forward by BASW, to which anyone caring for individuals who have a degree of capacity have to adhere to? (Mental Incapacity and Decision-making: Professional Implications for Social Workers (1998) page 12 refers). Or alternatively, a scheme whereby carers enter into a formal arrangement and/or Affidavit recognised in law such as suggested by BASW which was itself modelled along the lines of one proposed by the then Lord Chancellor’s Department (LCD) BASW Response to the White Paper: Making Decisions Release of Payments Scheme (2000) pages 15–16 refers).

8. to 22. *Lasting powers of attorney and appointment of Deputies*

(As an aside, it is good to see that the DoCA has taken heed of BASW's request to rename the power of attorney, indeed it seems to have adopted one of BASW's suggestions by replacing the Enduring Power of Attorney (EPA) with one of a Lasting Power of Attorney (LPA)! (BASW Response to the Green Paper: Who Decides? Making Decisions on Behalf of Mentally Incapacitated Adults (1998) page 26 refers)).

In order to prevent the continuing financial abuse and exploitation of people with reduced capacity that can take place under the current ad hoc arrangements, BASW has supported the idea of replacing the provision for Enduring Power of Attorney (EPA) and differing forms of making decisions of a welfare nature with a new power of attorney. BASW thought that this new power of attorney should:

- be subject to accreditation by an independent solicitor or clinician;
- have a certificate of notification;
- have a prescribed format;
- adhere to transparent decision-making processes;
- be accountable for his or her decisions; and
- submit reports of his or her dealings especially after for example, changes in circumstances and/or major expenditure.

(BASW Response to the Green Paper: Who Decides? Making Decisions on Behalf of Mentally Incapacitated Adults (1998) page 29 refers).

The Draft Bill goes some way to meeting BASW's criteria and, in all, this section dealing with the two new types of powers of attorney—LPA and Deputies—enabling decision-making to be made for and on behalf of vulnerable adults, covers approximately eight pages of the Draft Bill. I am not, however, convinced that the proposals, despite their volume, offer sufficient safeguards in the form of monitoring and review of either LPA's or Deputies.

There are some good things. I note that in the Explanatory Notes (page 30 refers) fluctuating capacity has been taken on board and the need to seek variation of the power of attorney when capacity is recovered. This is a very positive measure, as fluctuating capacity has tended to fall off the agenda in the past. But Clause 1.20 is only applicable to Deputies. I would like it also applied to LPA's. Otherwise, the arrangements for both LPA's and Deputies needs to be tightened as neither LPA's or Deputies appear to be time limited in any way; the payment of fees etc seems unstructured and almost random in both the Draft Bill and the Explanatory Notes; nor does there appear to be any regularised manner in which to update the power of attorney and/or carry out spot checks (BASW Response to the Green Paper: Who Decides? Making Decisions on Behalf of Mentally Incapacitated Adults (1998) page 26 refers).

Where, too, are provisions for the monitoring and support of carers performing these responsible roles, sometimes together with other donees who may be opposed to the carers' line of action in relation to someone who has reduced capacity? (BASW Response to the White Paper: Making Decisions Release of Payments Scheme (2000) pages 15–16 refers).

23. to 25. *Advance decisions to refuse treatment:*

BASW has always acknowledged that legislation associated with Advance Directives is currently confused and has consistently supported the need to clarify common law in this area (Mental Incapacity and Decision-making: Professional Implication for Social Workers (1998) pages 19–21 refer).

However, although there have been many advances in case law during the past five years, this remains a very delicate issue and it is one on which the last attempt to pass legislation on mental incapacity foundered in 1995. On a personal level, I'm surprised to see it included in this Draft Bill. I note from the newspapers that there have already been protests about the Bill, with suggestions that it will legitimise euthanasia by neglect, so I'll be even more surprised if it survives but we shall see.

30. *Codes of Practice*

While there's a commitment to consult in both the Explanatory Notes and the Draft Mental Incapacity Bill, there's no commitment here to publish the Code of Practice at the same time as the legislation comes into force.

With the experience of the Mental Health Act of 1983 in mind, BASW has consistently called for any Code of Practice accompanying new mental incapacity legislation to be issued simultaneously to that new legislation being enacted (Mental Incapacity and Decision-making: professional Implications for Social Workers (1998) page 27 refers); BASW Response to the Green Paper: Who Decides? Making Decisions on Behalf of Mentally Incapacitated Adults (1998) page 35 refers); BASW Response to the White Paper: Making Decisions Release of Payments Scheme (2000) page 6 refers).

31. *Ill-treatment and neglect*

With the proviso that any new offence regarding the ill treatment and neglect of a vulnerable person would be a last resort, BASW was fully supportive of the introduction of legislation in this area when the suggestion was mooted in *Who Decides?* (BASW Response to the Green Paper: *Who Decides? Making Decisions on Behalf of Mentally Incapacitated Adults* (1998) page 39 refers).

The creation of a New Offence regarding the ill treatment and neglect of an individual with reduced capacity will surely mark a brave new world. But, in my view, it is this part of the Draft Bill that has the most serious shortcomings. The New Offence is a major innovation but I do not believe it goes far enough.

I think a further insertion is called for in terms of someone who may not commit an offence under the terms of 31 (a) or (b) but who may, nevertheless, allow, cause and/or incite others to mistreat, exploit and/or abuse a person with reduced capacity. I'm thinking of sexual abuse and/or prostitution in particular here and the provisions of 31(a) or (b) may not necessarily apply. In any case, I think that the penalties for such offences are far, far too light. Parity of esteem should be given to the principle of vulnerability. If they are to be any kind of worthwhile deterrent, then the sentences for these New Offences should on a par with those imposed on someone who abuses children.

In other respects, the creation of New Offences will inevitably impose a heavier workload on social workers in areas such as investigation and multi-agency collaboration; the preparation of social reports; and court appearances. Additional resources must accompany these measures as they will certainly incur extra costs and require more specialised training. And, if such measures are to be successfully implemented, they have to be accompanied by the appropriate input of training and resources; and importantly, a change of culture as social workers will have to work closely with the police and other agencies as allegations are taken through the criminal justice system.

Another shortcoming is the absence of any requirement to provide protection for a mentally incapacitated adult once a carer, or other party, who has been accused of an offence, is awaiting trial. Unfortunately, even within the framework of this Bill that provides for an assessment of someone's capacity, it is a salutary fact that there is no way in which a vulnerable individual with reduced capacity can be removed from an abusive and/or neglectful situation. This is a grave omission as apart from Section 47 of National Assistance Act (1948) the only course of action for this group of people is "de facto" detention within a mental institution or an inappropriate imposition of Section 1 of the MHA (83). This may result in a social worker involved with someone whose capacity is reduced and who is being abused, being faced with, on the one hand, an increased workload in the form of having more reports and interagency collaboration and on the other a remaining dearth of suitable provision for the individual concerned.

In such situations, prior to the conviction of someone who is ill treating and/or neglecting a person who is mentally incapacitated, it is possible that the abuse and/or neglect may continue demanding very considerable additional social care input.

After considering the matter in some detail, BASW recommended that circumstances in which the welfare of a mentally incapacitated individual is endangered or suspected of being so, should warrant investigation the imposition of a protection order (BASW Response to the Lord Chancellor's White Paper *Making Decisions Green Paper Who Decides* pages 37–43 refer).

PART 2

34. *The Court of Protection*

BASW has supported the idea of an updated Court of Protection as being mainly responsible for decision-making with and for individuals with reduced capacity. In BASW's view, providing the Court is modernised, user friendly, sufficiently staffed and resourced and has a meaningful regional presence, it should be well able to become a new superior court of record for this vulnerable group of people (BASW Response to the Green Paper: *Who Decides? Making Decisions on Behalf of Mentally Incapacitated Adults* (1998) pages 29–30 refer).

The Adults with Incapacity (Scotland) Act 2000 has had its teething problems and has taken time to bed down but it appears to have been founded on a person-centred approach. Superficially, this Draft Bill seems to be following the example of the Scottish model insofar as it has also adopted a Public Guardian as the pivot of the new superior court. BASW supported such an innovation when suggested in *Making Decisions* (2000) as the Association perceived it to be potentially the best means of ensuring that new legislation for mentally incapacitated adults would be effectively implemented. The Scottish model had dedicated resources attached to it from the outset and the Public Guardian had a central role within the Supreme Court and was thereby invested with the necessary level of authority from the start of the scheme (BASW Response to the White Paper: *Making Decisions Release of Payments Scheme* (2000) page 6 refers).

Unlike the Scottish example however, this Draft Bill does not propose the Public Guardian be part of the Supreme Court but instead part of a new superior court of record. The implications of such a move, together with the establishment of regional and/or county registries, are difficult to evaluate but one of the advantages of basing a new structure on the old Court of Protection was that the Court had built up an extensive body of knowledge and expertise regarding the management of the financial affairs of mentally incapacitated adults. Whether this will be dissipated by the introduction of new arrangements and whether the jurisdiction of the court will be adversely affected by such changes, is hard to judge.

The fees and costs incurred by reference to the new Court of Protection are an issue, as those charged by the old Court of Protection were often to the detriment of the vulnerable person concerned. In BASW's opinion, there should be no financial penalty attached to the Court of Protection (Mental Incapacity and Decision-making: Professional Implications to Social Workers (1998) page 23 refers).

CONCLUSION

If I examined the fine details of this Draft Bill I have no doubt that I would have other aspects to comment on. All told, although I was pleasantly surprised to see this Bill manifest itself after such a long, long period of gestation and then disappointed at its contents, I do think its provisions signify a means with which a social worker can assess a person's capacity and ensure that more appropriate procedures can be put in place to meet his/her special needs. It can be built on. It is progress of a sort.

August 2003

122. Memorandum from the Independent Healthcare Association (MIB 1207)

The Independent Healthcare Association—the leading voice of the UK's nongovernmental health & social care sector—very much supports the principle of the bill. The key will be getting the details right.

It is particularly important to ensure that the Incapacity Bill is compatible with, and complementary to, the draft Mental Health Bill. We would encourage your committee to look at how these two draft bills would interface with each other.

The situation is as follows:

- The Mental Health Bill (published by the Department of Health) seeks, among other things, to ensure people with mental health conditions who are being treated informally (ie, they have not been "sectioned") benefit from proper legal safeguards of the type that sectioned patients receive. The Government is seeking to close what has become known as the "Bournewood Gap", so-called after the case that first drew attention to the issue.
- The Mental Incapacity Bill (published by the Department of Constitutional Affairs) seeks to provide people who lack capacity (this would include a large proportion of people who are cared for by mental health providers) with the ability to appoint somebody with power of attorney over their health issues, similar to how it is already possible to appoint somebody to have power of attorney over financial issues.
- The question is: which bill would apply and in what circumstances?
- IHA understands that the list of conditions that will be covered by the Mental Health Bill has not yet been finalised. This has particular implications in the case of conditions such as Huntingdon's disease, Parkinson's disease, acquired brain injury, stroke patients and people with multiple sclerosis that develop mental health problems. With a such conditions, people may lose their capacity to make decisions—would the treatment of such people be regulated by mental health legislation or incapacity legislation?

The IHA would welcome a broad range of conditions being covered by the Mental Incapacity Bill. This would allow for more personal and more effective protection for patients, as well as being less bureaucratic for nursing homes, hospitals and other care providers. As yet, however, we have not had confirmation from officials of which conditions will be covered by which bill.

There are also other issues. For example, what mechanism will there be, in a lasting Power of Attorney, when the person appointed to act on behalf of the patient refuses treatment when the clinician (responsible under the Mental Health Bill) believes such a course of action to be against the patient's best interests?

We look forward to your committee's findings on the draft bill.

October 2003

123. Memorandum from the British Bankers' Association (MIB 1220)

Thank you for the opportunity to respond during the consultative phase of the draft mental incapacity bill and for extending the deadline for comment. This is a sensitive and complex area of law and one where bank branch staff are acutely aware of the potential risks and responsibilities that arise in the course of their dealing with those who act on behalf of a mentally incapacitated person (P).

The BBA has been working with its members on such issues for the past year and has recently published guidance for bank branch staff to assist them in their dealings with Attorneys (A) and Deputies (D). A copy of the guidance is enclosed.

SPECIFIC OPERATIONAL ISSUES RAISED BY THE DRAFT BILL

1. *Point of registration of a Lasting Power of Attorney (formerly an EPA)*

The draft Bill proposes that the new LPA is registered when that power is granted, rather than as present, when the donor of the power is or is becoming mentally incapable. The difficulty in this approach, however, is determining the point at which the donor is actually incapable and thus the point at which a bank is correct to deal only with the A. It is at the point of registration that banks' treat the Donor as being incapable and will only act on the instructions of A. The current treatment of Donors and A, therefore, is driven by registration of the LPA, which is entirely practical, and we are concerned that changing the point at which LPA registration takes place will give rise to serious operational difficulties for bank branch staff. If the LPA is to be registered as soon as it is granted, banks will not be apply the same rule because there can be no presumption of mental incapacity.

- We would urge the Joint Committee to leave unaltered the current process for registration of an LPA.

2. *Clause 6—the General Authority*

As discussed above, registration of an LPA or award of a Court Order provides certainty for bank branch staff in appropriately identifying when and with whom they should liaise on behalf of P; the LPA or Court order providing "evidence" of their authority to act. However, where there is no LPA or Court Order and, particularly where P is in receipt of direct benefit payments and/or Local Authority Payments, there are reputational risks to banks (i) should they allow access to P's account where there is no evidence of proper authorisation, but equally (ii) if they do not allow access to P's account and P is unable to gain access to benefit because it has been paid directly into their bank account.

Given this dichotomous reputational risk to banks should they permit/not permit access to P's bank account, BBA members are currently considering whether a third party "Appointee" should be able to open or operate a bank account on behalf of P. We would envisage an 'Appointee' would only be permitted to operate a P account in a specific set of circumstances (such as account turnover of less than £2,000 per month), and are raising this with relevant bodies such as the Public Guardianship Office, the Department for Work and Pensions and the Department for Health.

In allowing an "Appointee" access to a P bank account, our members would also first wish to satisfy themselves:

- (a) That they can deal with a third party 'Appointee' under the provisions of the bill,
- (b) With whom they are dealing, and
- (c) In what capacity the 'Appointee' is acting on behalf of P

At first glance, Clause 6 appears to grant third parties authority to handle P's money where necessities are to be paid, yet paragraph 36 of the Explanatory Note to the bill goes on to say that,

Sub sections 2 and 3 need to be read with clause 33 (P must pay a reasonable price for necessary goods and services supplied). If a person acting under the general authority arranges something for P which costs money then the person can promise that P will pay, use money which P has in his possession, pay himself back from P's money in his possession or consider himself owed by P. *These sub sections do not allow access to funds held by, for example, P's bank or building society account.*

This then suggests that those who act on behalf of P should not have access to P's bank or building society under the General Authority. In view of the concerns we have outlined above, it would be helpful if the relationship between the draft bill and the corresponding Explanatory Note were clarified. It would further seem appropriate that the bill include a deeming provision for third parties, i.e. that the third party may be deemed by the bank to have authority to act on behalf of P where the third party is able to provide confirmation of this. This might, for example, take the form of a letter from the Benefits Agency or the Local Authority.

- The relationship between Clause 6 and the Explanatory Note concerning access to P's bank or building society account should be clarified, bearing in mind the difficulties posed to P where there is no LPA or Court Order and P is in receipt of benefits paid directly into a bank account and/or Local Authority Direct Payments.

- Consideration should also be given to establishing a minimum threshold amount that could be withdrawn by a third party ‘Appointee’ which would provide further clarity and legal certainty.

OTHER GENERAL COMMENTS

1. *Clause 3*

There appears to be an inconsistency between Clause 3, which says that incapacity must be firmly established and there is a presumption of capacity, and the rest of the bill, where the general authority can be exercised where it is reasonably believed P has lost capacity.

2. *Clause 12 (5) (c)*

These sub sections refer to the annulment or dissolution of a marriage but perhaps this should also include a provision, where there is already an Attorney, to enable the spouse of the Donor to become the Attorney following a subsequent marriage.

3. *Clause 34—the Court of Protection*

We would welcome clarity on the approach of the Court of Protection where an individual’s assets or income is not considered sufficient to warrant the involvement of the Court. Presently, the bill is silent in this respect yet we understand that, in practice, the Court may not become involved unless certain monetary criteria is met.

We would appreciate being kept informed of developments and should you require any further clarification on any of the points we have raised, please do not hesitate to contact me.

Samantha Mitchell
Director

October 2003

124. Memorandum from Martin Terrell (MIB 1002)

INTRODUCTION

1. I make this submission as a solicitor in private practice with experience in dealing with the affairs of elderly clients. I have over 10 years’ experience in this area of work and have a detailed knowledge of the legal and practical issues involved.

2. I have written chapters on the financial management of the affairs of elderly clients for *Tolley’s Finance & Law for the Older Client* and *Butterworths’ Older Client Law Service*. I have also contributed a number of chapters to *Heywood & Massey: Court of Protection Practice* and have written my own book *A Practitioner’s Guide to the Court of Protection* which was published last year by Tolley’s. I am currently working on the 2nd edition of this book and am editing the Law Society’s *Elderly Client Handbook*. As well as editing this book, I have written a chapter dealing specifically with the financial affairs of elderly clients.

3. I am also a Panel Receiver and a member of the Professional Receivers Forum of the Public Guardianship Office.

LACK OF PREPARATION

4. My principle concern about the draft Bill is that it has been prepared with the best intentions but without a great deal of thought to its practical implications “on the ground”. It will be practitioners such as myself who will need to deal with its implementation. The lack of thought that has gone into this is emphasised by an email sent to a colleague from the Mental Incapacity Bill Team of the DCA on 8 August stating:

“I am approaching a number of our stakeholders to ask them if they can help me obtain a clearer idea of these practical benefits and I hope that you would be willing to provide me with some information from your specific area if possible.”

The correspondent sent this email on 8 August and asked for replies by 18 August. This does indicate that the draughtsmen have placed the “cart before the horse” in drafting this legislation.

5. My own view is that legislation needs to work backwards in terms of identifying the issues involved, the problems with the existing legislation and where improvements may be made. The main problem with the existing legislation is that the Enduring Power of Attorney system provides inadequate safeguards for the elderly and vulnerable individual. In a widely quoted comment, the Master of the Court of Protection has stated that some 10–15% of Enduring Powers of Attorney are used improperly or fraudulently (Cretney & Lush 5th edition, para 12.1):

“financial abuse probably occurs in about 10–15% of cases. Expressed as a percentage this may seem to be a relatively minor problem, and maybe even an acceptable price to pay for the 8S–90% of cases where attorneys act lawfully.”

LACK OF PROTECTION

6. I have in my own experience dealt with a case where a nursing home manager obtained Enduring Powers of Attorney from a number of elderly residents who had no relatives at hand and systematically defrauded them of over £500,000. Eventually the fraud was detected and the manager was prosecuted by the police. Unfortunately, not all the monies stolen were recovered and several charges were dropped through lack of evidence. The persons who could supply evidence were either mentally incapable or had by then passed away and a great injustice has been allowed to take place.

7. The proposed legislation does nothing to address this type of situation. There are no additional safeguards available to the donor of a lasting power of attorney. The existing safeguard that all relatives of certain categories are to be notified has been removed and replaced by a requirement that only specified persons are notified.

8. I am also concerned by the proposal that the powers of the donee of a lasting power of attorney should, under clause 10 of the proposed Bill, extend to decisions about personal welfare and may, if the lasting power of attorney contains provisions to that effect, extend to refusing consent to the carrying out or continuation of life sustaining treatment. This effectively gives the attorney power of life and death over the donor. The Bill does not take account of the practical consequences of this situation.

9. In the vast majority of such cases there is absolutely no dispute over what is appropriate for the incapable person. To the extent possible the capable person gives his or her own consent, relatives are consulted and doctors can then determine what is in that person's “best interests”. Problems only arise where there is disagreement and generally a dispute between relatives over where a person should live, whether treatment should be prolonged or whether treatment should be curtailed. Often these situations are extremely painful and difficult for all concerned. In an ideal world, it is perhaps tempting to give someone (the donee of a lasting power of attorney or a manager appointed by a court) to make the final decision. This also allows doctors to avoid making awkward decisions or getting involved in family arguments.

10. The problem inherent in the draft Bill is that a decision by a third party is only necessary where there is a dispute and at least two alternative decisions that can be made. In my own view, an attorney or manager is not the best person to make a decision in this type of situation for the following reasons:

- The donee/manager is generally not medically qualified.
- The donee/manager is partisan in that he or she is proposing one course of action which another person opposes.
- The donee/manager will either be a professional who should not be presented with moral dilemmas of this nature or a relative who in most cases will have an obvious conflict of interest.

CONFLICTS OF INTEREST

11. I would like to elaborate on this last point in more detail and it has been completely overlooked in the legislation. It is a basic principle in litigation where you are acting on behalf an incapable person that you have no conflict of interest. A donee/manager who is a relative may also be a beneficiary under the person's will or intestacy and therefore has a clear conflict of interest. This may be an irrelevant consideration in most families where the welfare of the individual is paramount. However, a conflict arises whether or not it is real, it simply has to be a potential conflict. The danger is nevertheless real that medical and welfare decisions will be influenced by financial considerations.

12. I appreciate that in many cases attorneys already act where financial decisions are made which will affect their inheritance later on. However, the power only relates to financial decisions and an attorney has a fiduciary duty towards the donor's estate. A receiver has a duty to the Court of Protection and if a solicitor, a professional duty as well, to act exclusively in the patient's best interests. However, the attorney/receiver has no direct control over a person's accommodation or treatment. Generally, accommodation and treatment are dictated by a person's needs rather than by their resources. The danger of the proposed Bill is that it will become much easier for a beneficiary under a person's will or intestacy to dictate where he or she lives and how he should be treated. If I, as an attorney, who is also a beneficiary, can see my inheritance disappearing in nursing home fees, am I not going to be influenced by this when choosing the nursing home and determining whether proposed treatment might prolong the person's life?

13. To bring these concerns to a conclusion, I would argue strongly that lasting powers of attorney should have no place in this Bill. They add nothing to the existing arrangements available under Enduring Powers of Attorney and if anything weaken the safeguards already available to donors of Enduring Powers of Attorney. There are improvements that can be made to Enduring Powers of Attorney through legislation as well as through administrative practice, but these are not addressed in the proposed legislation.

ADVANCE DECISIONS

14. For similar reasons, I am also concerned by the proposed legislation concerning advance decisions. My understanding is that the law already recognises advance refusals in certain situations but advanced decisions opens up the whole minefield of moral issues, medical ethics and risk. There is no ideal legislative framework for this type of situation which protects the patient, the doctor as well as the relatives. It is extraordinary that an advance decision might be verbal. If my elderly relative tells me in the pub that he doesn't want to "end up" in a particular way, then that constitutes a valid advance decision. If I then communicate that decision to a doctor, who is perhaps under pressure from his managers to free up a much needed hospital bed and act in accordance with my evidence, my elderly relative's treatment can be withdrawn, with death being the result. Both the doctor and I are protected by clause 25(3) of the bill as long as we believe that the decision was valid.

15. I would strongly advise therefore that the provisions of this draft Bill relating to lasting powers of attorney and advanced decisions are removed.

16. I can see no objection however to the Court's powers to make decisions being set out in a statutory framework. All this would do would be to transfer the existing jurisdiction of the High Court to make declaratory judgements to the new Court of Protection. The advantage of a court making these decisions is that a court can take a strictly objective view of a person's "best interests" and can look at all the evidence. Soundings can be taken from different relatives and the court can take independent advice from social workers, doctors, solicitors involved in the case or concerned friends, neighbours and relatives. In sensitive cases where there is an obvious conflict of interest, the Official Solicitor can also act to represent the incapable person. All that the proposed Bill would do, it seems, is to make this jurisdiction more accessible to a wider public.

17. If this is the outcome of the Bill then there will be a positive advantage to it. However, some thought needs to be given to the way in which the jurisdiction will be established and its cost implications. I doubt whether in numerical terms the High Court deals with many such cases each year. If it were perceived that a more local and cost effective solution were available nearby, would it not encourage people to take advantage of it and air their grievances through this court? From a practitioner's point of view, I notice families becoming ever more disputatious and prone to argument over these issues. Litigation though is often avoided simply by the High Court jurisdiction not being widely understood and also being very expensive to pursue. If a more accessible and more affordable jurisdiction were available locally, it could potentially increase the appetite for litigation in these situations. Has any thought been given to the resources required? How will judges implement the court's jurisdiction and what resources will be required?

DEFINITIONS OF CAPACITY

18. My last concern relates to the definition of capacity and how this impacts in practice. For example, the jurisdiction of the Court of Protection may be relevant where lack of capacity is temporary or relates to only one aspect of a person's affairs. How are professionals let alone third parties such as banks supposed to deal with these situations? If a person is presumed capable and a manager has been appointed, where does the presumption of capacity lie?

19. It is also unclear what degree of incapacity is required. The present legislation refers to "mental disorder" whereas the draft Bill refers to an "impairment in the functioning of the mind." Would this for instance include someone who is now alcoholic or has fits of depression?

20. A person also appears to be incapable if he is unable to communicate a decision. I have recently dealt with a stroke victim who understood very clearly what was going on around her but could not communicate except in very general terms. According to the Bill, she would be deemed to be incapable. Clause 2 of the Bill tries to refine in five short paragraphs a vast range of situations which the courts have struggled with in determining whether or not a person is capable. To the credit of the courts they have been somewhat flexible in interpreting the existing law as it stands, but it is very difficult to apply precise definitions to different situations. In a recent case an elderly gentleman gave £200,000 to his next door neighbour. His estate was worth only £230,000 and apparently he fully understood what he was doing. According to the draft Bill, he would be treated under clause 2(2) as able to make an "unwise decision" and under clause 3 he would be deemed to be capable. In this particular case, the court was able to set aside the gift because the decision was irrational and could not have been property thought through by the individual.

21. I do not believe you would expect a line by line analysis of the Bill but I can provide a more detailed response if this might be helpful. In view of the short timescale provided one can only respond to the proposed Bill in very general terms and hope that these considerations will be of assistance.

22. The comments set out in this submission represent my own views and not those of my partners or firm.

September 2003

125. Memorandum from Right to Life (MIB 1017)

We welcome a legal framework for decision-making in the care of the elderly, embracing financial and health and welfare interests. However, we consider that some of the clauses and concepts in the Draft Mental Incapacity Bill could weaken the rights of the elderly and mentally incapacitated, particularly in relation to the right to life.

In introducing our Submission we would stress that the European Convention on Human Rights recognises the right to life as the fundamental right, the condition of all other rights.

Article 2 of the Convention states

“Everyone’s right to life shall be protected. No-one shall be deprived of life intentionally . . .”

This requires of the State a positive obligation to take appropriate steps to protect innocent citizens from any act or omission deliberately intended to deprive them of life.

We urge, therefore, that the Committee should take into account the following points which we consider would jeopardise the healthcare of the elderly and mentally incapacitated.

SECTION 4

Best Interests

The definition of “Best Interests” in the Bill and explanatory notes confuses wishes and autonomy with the actual well-being of patients. In parts the drafting is so vague that it could mean that a patient’s wishes might include a chance remark he or she has made while watching a television programme. This would be allowed under the guise of “autonomy”.

We urge that objective medical criteria should be written into the Bill to define best interests. Where possible this should include the restoration and maintenance of health. Where no cure is possible, the Bill should require control of symptoms (including pain) and basic care, including assisted food and fluid (hunger is not an illness).

As the Bill stands there is nothing in it to protect patients from relatives and others who are motivated by self-interest. Proper protection must be provided as far as possible by objective criteria.

Powers of Attorney and Proxies

RTL agrees with the concepts of Powers of Attorney and Proxies. However, any action taken must be in accordance with the Best Interests of the Patient. No Proxy or person with a Power of Attorney should be permitted to authorise the withholding or withdrawal of treatment with the purpose of ending life. At the same time we recognise the validity of the withdrawal of treatment (including assisted food and fluid) if the decision is made because the treatment is burdensome or in cases where it is known to be futile. We would also add that in our experience relatives and friends who are appointed as proxies by patients are usually extremely responsible regarding the health care of patients.

Nonetheless, doctors, nurses or others (including relatives) concerned about the conduct or behaviour of a Proxy or somebody with Powers of Attorney must have speedy access to appeal. We recommend that a System of Appeal should be written into the Bill rather than those concerned having to apply to the Court of Protection for permission to appeal as is proposed in the current Draft Bill. As the Bill is drafted Senior Counsel has advised that it contravenes Article 6 of the European Convention on Human Rights which safeguards all citizens access to the courts.

Advance Directives or “Living Wills”

This matter was considered in depth by the House of Lords Select Committee on Medical Ethics (1994), the Report of which both the Government and the Conservative Party claim to support. The Committee took evidence from the British Medical Association, the Crown Prosecution Service, the Royal College of Nursing, The National Hospice Council, the Law Society, and the Law Commission among others.

In its Report the Select Committee stated that there was no *definitive* case making *all* advance directives legally binding. Although it welcomed the use of advance directives, it strongly recommended that no legislation should be introduced to give them greater legal force.

They listed a number of problems and difficulties which could arise through doctors being compelled to follow advance directives regardless of the circumstances or the outcome. They also pointed out that patients could be deprived of the most up-to-date treatment, developed after they had signed advance directives. Other problems they considered were advance directives made by patients under pressure, living wills made by patients who had not considered the particular illness or affliction doctors were treating, directives made many years previously—thus not allowing for a change of mind.

We fail to understand why the Government should be so insistent upon making Advance Directives legally binding, thus breaking their promises to support the recommendations of the House of Lords Select Committee. We urge that the Standing Committee should challenge the Government on its claim that according to “case law” advance directives are legally binding and that doctors failing to observe them could be guilty of assault. The Government should be required to cite a “definitive” case making all advance directives legally binding, particularly as the House of Lords Select Committee on Medical Ethics stated—there had been no such “definitive case”.

The results of a survey conducted by ORB (Opinion Research Business) among 986 doctors in April 2003 showed that 71% would be unwilling to follow an advance directive in certain circumstances. The problems they listed reflected the problems given by the House of Lords Select Committee as to why they opposed Statute Law which would make advance directives legally binding.

ORB has submitted the results of the survey on the matter of Legally Binding Advance Directives to the Standing Committee and we urge that the members should take it into account. We also urge the Standing Committee to follow the recommendations of the 1994 Lords’ Committee and reject the clauses in the Draft Mental Incapacity Bill relating to advance directives. We repeat: both the Government and the Conservative Party have claimed to support the recommendations of the Select Committee. As the Bill stands it could seriously jeopardise the rights of the elderly and the mentally incapacitated.

Finally, we would point out that the ORB survey showed a considerably higher proportion of doctors who support euthanasia and assisted suicide would follow advance directives regardless of the circumstances than was the case among doctors opposed to such practices.

The Withdrawal of Assisted Food and Fluid with the Purpose of Causing Death

The present draft of the Mental Incapacity Bill would allow the withdrawal of assisted food and fluid with the purpose of ending the life of a mentally incapacitated patient. This is “achieved” by describing assisted food and fluid as “treatment”. However, thirst and hunger are not diseases. They are natural physical reactions experienced by the whole of mankind and to ignore them is an act of sheer cruelty.

We urge that the standing Committee should include the Baroness Knight’s Patients’ Protection Bill as a clause in the Mental Incapacity Bill; this, with the amendments tabled by Baroness Knight of Collingtree and Professor Baroness Finlay of Llandaff, would follow good medical practice as followed in the Hospice Movement.

September 2003

126. Memorandum from Mrs Josie Goble (MIB 1025)

A caring society rightly seeks to minimise suffering and do its best for all citizens. There are however often many snags in the best of endeavours and it is well that a Bill such as the one above is treated with extreme caution.

As far as I know this Bill has been compiled by people who have not had strokes, been in PVS or yet suffered with dementia. The thought of these misfortunes brings shudders of horror and all too often the feeling that death would be preferable. Accordingly there is the thought that Advance Directives should be encouraged and so-called mercy killing legalised. I believe these ideas are wrong—that we cannot tell how we would feel in a particular situation until we are actually there.

I worked for 15 years in an Old People’s Home where I met and served a great variety of clients including many stroke and dementia victims. The whole ethos of the establishment was to bring to its occupants the best standard of living that we could and encourage them over and around their difficulties.

I enclose my submission regarding this Bill in the form of a chart which I hope will be useful.

SUBMISSION CHART CONCERNING THE DRAFT MENTAL INCAPACITY BILL		
Subject	Conjecture	Fact
1. Advance Directives.	(a) That we know how we would feel in a given situation.	That we cannot possibly know how we would feel in a situation not yet experienced.
	(b) That our AD would be easily available and useful as required.	We might die painfully whilst the AD was being located and read, ie no resuscitation or other first aid attempted for fear the AD contained wishes to the contrary.
	(c) That there would be no new forms of treatment available.	New forms of treatment may be available.
	(d) That ADs would only be signed by people of sound strong mind.	Vulnerable people will be persuaded to make statements they might otherwise not have made, by relatives set to gain by that person's death. This already happens with ordinary wills.
2. Lasting Power of Attorney.	(a) That the LPA would be trustworthy and act in the best interests of the patient.	There would be many who were not trustworthy and who would act in their own interest rather than the patient's (see (d) above).
	(b) That, where the Attorney is also the carer, they will have everlasting powers of endurance.	The best people in the world are subject to growing tired, disillusioned and tempted.
3. Tube feeding.	(a) That because a person is unconscious or can be given a flannel to suck, they will feel no pain.	Starvation and dehydration are extremely painful.
	(b) That because nourishment is given by means of tubes it becomes medical treatment.	Only if the tubes carry medicine are they medical treatment in the same way as a piece of lint cannot be termed a "dressing" until it is impregnated with some form of medication.
4. Ending suffering.	(a) A person in a bad mental/physical state is better off dead.	Conditions change—even when conditions have worsened, the adaptability factor quite often improves. Also, there have been many cases of coma victims recovering.
	(b) That suffering automatically stops at death.	No-one knows for sure that this is the case. There are many theories that life continues.
	(c) Suffering is so severe it cannot be eased.	Palliative care is now highly efficient.
	(d) We put animals out of their misery, therefore we should do likewise to humans.	See above (4c), but—more importantly—there is a vital difference between mankind and animals.

August 2003

127. Memorandum from the Scottish Council on Human Bioethics Limited (MIB 1029)

The Scottish Council on Human Bioethics is an independent, non-partisan group of doctors, lawyers, psychologists, ethicists and other professionals from disciplines associated with medical ethics. The principles to which we subscribe are set out in the United Nations Universal Declaration of Human Rights which was adopted and proclaimed by the UN General Assembly by resolution 217A (III) on 10 December 1948.

Our aims include the assessment and analysis of policy proposals from an ethical perspective.

We were involved in commenting on the Adults with Incapacity (Scotland) Act 2000 during its passage through the Scottish Parliament. We gave evidence to the Parliament's Justice and Health Committees and met with Ministers and Civil Servants to discuss aspects of the Bill.

RESPONSE TO DRAFT MENTAL INCAPACITY BILL

One point we would make at the outset is that insufficient time has been allowed for consultation on this Bill. The consultation has coincided with the holiday period and even the customary minimum time for responses (in our experience three months) has not been allowed.

Given the shortage of time, we have restricted ourselves to commenting only on the legal and medical aspects of the Bill as they relate to decisions about medical treatment made on behalf of those with incapacity. Had we had more time, we would also have liked to comment on the effect of the Scottish Act on medical practice north of the border.

1. Overview

1.1 One matter which is immediately striking about this Bill is the extent to which it changes the balance of power in the healthcare setting. Although we understand from the accompanying Ministerial Foreword, that the stated aim is to empower those with incapacity, in practical terms, this Bill would have the opposite effect.

1.2 Under the Bill the legal protection currently given to vulnerable incapable people will be substantially reduced¹³⁰. In particular, the Bill would allow passive involuntary euthanasia to be practised on incapable people whose lives are deemed by doctors or proxy decision-makers not to benefit them. It is imperative to preserve and, indeed enhance existing legal protection for incapable people because they are so vulnerable.

1.3 We consider that the Bill "dumbs down" the protection currently accorded to this vulnerable group in the following ways. It removes basic protection by redefining "best interests" to make it a subjective test in clause 4 and by creating proxy decision makers who will have power to refuse medical treatment on non-medical grounds. The principles of the Bill upon which patient protection depends (clause 4) are not capable of being objectively established by reliable evidence in all cases.

2. Best interests

2.1 In the commentary issued with the Bill, it is implied that the common law "best interests" principle is enshrined in the Bill. This appears somewhat disingenuous. At common law, a doctor can lawfully provide treatment to an adult incapable of giving consent provided the treatment is in the patient's best interests. In this context, at common law, "best interests" means treatment given to save the patient's life, or to improve or prevent deterioration of the patient's physical or mental health.¹³¹

2.2 This Bill does not enshrine that principle, it enshrines something quite different. The "new best interests test" in Section 4 is a guiding principle which doctors and proxies must use in deciding whether to give or authorise medical treatment (including tube feeding and fluids) under the Bill. Doctors must use it in deciding whether to give or withhold treatment under clause 6. Proxies must use it in deciding whether to refuse treatment under clause 8(1)(a) or 17(1)(d) (they have no power to compel treatment, only to refuse it). The Court of Protection must use it in resolving any disputes about whether "treatment" should be provided.

2.3 At common law, it is relatively simple to establish whether a given treatment is appropriate in terms of saving life, preventing deterioration etc. This can be proved reasonably objectively on the basis of evidence of physical examination of the patient and expert testimony as to the treatment proposed.

However, the new "best interests" test proposed introduces factors which are much more subjective such as alleged oral expressions of past wishes and feelings; views of carers and others as to what factors the person would consider if he were capable etc. As explained below, research in America appears to show that the possibility of a proxy actually choosing as the patient would have done is little better than chance. The effect of introducing a vague and subjective test is to remove such protection as currently exists. This leaves the law open to abuse by the unscrupulous.

¹³⁰ As Professor McLean pointed out in her evidence to the Justice and Home Affairs Committee during the passage of the Scottish Act, it will amount to no more than an assumption that a proxy decision maker will act in good faith. Official Report — Scottish Parliament JHAC 17 November 1999.

¹³¹ Re F 1990 2 AC 1.

3. *Proxy decision makers—power without responsibility*

3.1 This Bill fails to safeguard people with incapacity from passive euthanasia and perverse decisions and abuses of power by proxy decision makers.

3.2 The proxy decision makers created by the Bill can take decisions in relation to healthcare and also financial and property matters on behalf of adults with incapacity. It is likely that some proxy decision makers who have powers in both areas will face conflicts of interest. For example, the proxy may be a prospective beneficiary in the adult's estate and may be called upon to decide whether or not the adult should receive life sustaining medical treatment. It is possible that such a treatment decision may be taken in circumstances where, if life sustaining treatment is refused or withdrawn, there will be more money available for beneficiaries because nursing or care home fees will be saved.

3.3 In its memorandum to the Justice and Home Affairs Committee of the Scottish Parliament during the passage of the Adults with Incapacity (Scotland) Act 2000 dated 11 November 1999 the Scottish Neurological Consultants' Forum said "a . . . difficulty arises when close relatives appear not to be acting in the best interests of the patient; this is not common but neither is it rare". [Note that they are referring here to clinical best interests and not to the new test proposed.]

3.4 It is very important to recognise that while the majority of proxy decision makers can be presumed to be acting in good faith in what they believe to be the best interests of the incapable person, there are those who would not do so. (Almost all of our medical members questioned about this can relate such instances from their own experience).

No duty of Care

3.5 Incapable people are currently protected at least to some extent because doctors have a duty of care in relation to medical decisions taken on their behalf and can be prosecuted, sued or disciplined for breaching their duties to patients (depending on the gravity of the breach). However, proxies are not subject to the same duties or standards of care and they cannot therefore be prosecuted or sued for breaching or falling below them.

3.6 This means is that if proxies refuse say tube-feeding or insulin on behalf of the patient and thus cause the patient's death, they cannot be held liable. All they need claim is that the patient once expressed a wish not to have the treatment in these circumstances (section 4(2)(c)(I)) or that they thought the treatment was 'not in their best interests' under section 4(1). Alternatively, where the patient had an advance directive or was even believed to have one, this would be binding. Even if the patient was alleged to have made a past remark, this would be taken as evidence of past wishes and feelings about treatment under clause 4 and treatment would be denied. The evidential problems are obvious. Since the Bill entitles a proxy to refuse treatment subject only to the guiding principles, then provided he can bring himself within these as suggested above, neither the criminal law nor the civil law can touch him. The doctor could not be prosecuted either because she would have no authority to treat in the face of a refusal by a proxy. Although she has the option of appealing against this refusal to the Court of Protection, she has no obligation to do so.

3.7 A closer examination of the Bill's guiding principles and the common law makes it clear that if the Bill were enacted in its present form it would be almost impossible to successfully prosecute a proxy or doctor who caused the death of a person with incapacity by withholding or refusing treatment.

3.8 As Professor McLean said "I am not sure on what basis you could challenge them because a proxy decision maker could always say they that they had acted in good faith"¹³². At the Scottish Parliament's Justice Committee Meeting on 17 November Ben Wallace MSP asked Professor McLean¹³³ "Are you saying there is no way of putting a safeguard on the actions of a proxy?" She replied "I cannot think of any way that would do more than allow us to make the presumption that the person is acting in good faith." She went on to describe research in the USA which suggested that the possibility of a proxy making the same decision as the patient himself would have made is little better than chance.

3.9 If this research is correct, it suggests that this Bill removes vital protection from vulnerable people without conferring any benefit on them in terms of increased autonomy. In practical terms it is difficult to see any justification or ethical benefit from the medical aspects of this Bill. Some of the financial aspects of the Scottish Act were actually necessary but the medical sections have caused confusion and an increased burden of bureaucracy on doctors without improving the healthcare of adults with incapacity to any marked extent.

¹³² Col 395 17 November.

¹³³ Justice Cttee transcript 17.11.99 at para 400.

4. Advance refusals of treatment

4.1 In the green paper which preceded the Scottish Act, the Scottish Executive made the following statement:

“We have examined carefully a number of other proposals made by the Scottish Law commission, by the Alliance for the Promotion of the Incapable Adults Bill, and by others. Such proposals have included legislation to give clear legal force to Advance statements (“Living Wills”) and to provide for the withholding or withdrawal of treatment from patients who may be in . . . PVS. Although such proposals have the sincere support of particular interest groups, we do not consider that they command general support. Attempts to legislate in this area will not adequately cover all situations which might arise, and could produce unintended and undesirable results in individual cases.”¹³⁴

We share the Executive’s concern in relation to Advance Directives or refusals of treatment for the following reasons:

- They are open to abuse, particularly where, as here, it is proposed that they may be oral. Patients may have been coerced into making them or may have simply made them because they feared being a burden on relatives. They may have been depressed or have been experiencing feelings of low self worth.
- It may be difficult to establish retrospectively whether the person had capacity at the time of making the advance refusal. It is unclear what level of capacity is required in order to revoke a refusal, once made.
- If a person makes such a decision in advance it is unlikely that they will have access to medical advice and to all the relevant clinical considerations needed to make a good decision. Such decisions may be made in ignorance of important factors. They may increasingly be made on the basis of unreliable medical information downloaded from dubious web sites. This may also become a problem in relation to proxies who may be tempted to act as “amateur clinicians”.
- It may be very difficult to prove what circumstances were or were not anticipated by the patient at the time of the advance decision for the purposes of challenging validity under clause 24(4)(c).
- Advance refusals of treatment will mean that some patients will receive sub-optimal care. This will inevitably mean that patients who might otherwise have been rehabilitated will not receive treatment they need and may then require hospital care on a long term basis with consequent implications for allocation of resources.

August 2003

128. Memorandum from Dr I M Jessiman (MIB 1044)

The current legal position of those over 18 who lack capacity to give or withhold consent is undoubtedly unsatisfactory. In its attempt to overcome this problem, however, the present bill introduces several dangerous concepts particularly with respect to matters of medical care, most especially at the end of life.

The proposals for advance directives, notwithstanding the intended clarity of section 24, are far too vague and ill-defined. On the other hand, at least as far as medical matters are concerned, the proposals for lasting power of attorney give the attorney dangerously wide and unrestricted powers over life and death.

3. Presumption against lack of capacity

3(1) It is absolutely right that a persons’ capacity should be assumed unless it is established otherwise, but (at 3(2)) I am concerned that a lack of capacity is to be judged only on the balance of probabilities, albeit after “all practicable steps” have been taken [to help him make a decision]. “All practicable steps” (at 2(3)) is capable of very loose interpretation and could serve as a cloak for inadequate enquiry. The “balance of probabilities” test undermines the proper establishment of lack of capacity: Particularly with regard to decisions on matters of life and death, incapacity ought to be established “beyond reasonable doubt”. On the other hand, for the “re-establishment” of capacity the “balance of probabilities” test should apply.

4. Best interests

4(1), 4(2) The overriding importance of “best interests” is rightly highlighted early in the paper. However, medical best interests receive no mention. The whole ethos, indeed the whole practice, of medicine depends on the pursuit of the medical best interests of the patient. If this is not the case medicine is without motive and there are no criteria by which to measure its value. The recent booklet “A guide for healthcare professionals” (p 8), from the series “Making Decisions: Helping people who have difficulty deciding for

¹³⁴ *Making the Right Moves* published by the Scottish Executive 1999 <http://www.scotland.gov.uk/rightmoves/docs>

themselves” (Lord Chancellor’s Dept, 2003) it is noted that “Healthcare professionals can and should provide treatment without consent for people who lack capacity to consent, if it is considered to be clinically necessary and in the “*best interests*’ of the patient” . . . “Healthcare professionals have no authority to make any other sorts of decision, such as personal or welfare decisions.” “In relation to medical treatment, the High Court has ruled that “best interests are not confined to best medical interests . . .” The underlying assumption behind these paragraphs is the fundamental importance of medical best interests.

If medical best interests are to be subordinated to the unguided decisions (opinions) of lay people on medical matters (other than those of the patient himself, eg an attorney or deputy) then the whole basis of medical practice is undermined and in effect meaningless. Doctors’ and nurses’ skills are devalued and they are prevented from doing their best for the patient.

4(4) It is accepted that a patient may have good reason, bad reason, or no reason at all, for refusing a particular treatment, but a third party, whether an attorney or a deputy, should not have power or authority to make decisions without any corresponding responsibility—ie without having adequate and explicable reasons. For this reason 4(4) is unacceptable in medical matters. Doctors and nurses can be held liable for any failure to give the best possible [ie proper] medical care. The wide scope of this section (“the person reasonably believes what he does . . .”) is such that no attorney or deputy could ever be found liable, however gross a violation of “best interests” they may perpetrate. It would not appear impossible for doctors and nurses to be held liable for failing to provide “proper” care for a patient where the attorney or deputy had flagrantly refused it (and maybe later denied so doing).

6–7. *The general authority Restrictions on the general authority*

I do not consider it right for an attorney or deputy, still less for a person acting under “general authority” to be able to refuse “life-sustaining treatment”. As mentioned above (at 4 (4)), I believe that such an exercise of authority, without responsibility or being answerable to anyone, undermines the whole basis of medical practice.

10. *Scope of lasting powers of attorney: personal welfare*

Subject to the comments on “best interests” at 4 above, 10(3) and 10(4)(b) are acceptable, but no attorney or deputy should have authority to refuse basic care or to refuse consent to life-sustaining treatment.

10(4)(a) It is not clear when, or indeed how, “P’s” capacity is to be assessed in this context. 10(4)(a) seems to indicate that if “P” has capacity at the relevant moment he can exercise it, but Schedule 3, Part 4, 14 (1)(a),(b),(c) and 14(2) clearly indicates otherwise.

Once the power (in the instrument) has been registered, the paragraphs (in Schedule 3, Part 4) just cited would appear to leave the donor “incapable” of accepting or refusing the carrying out or continuation of any treatment whatsoever, at least until the matter can be reconsidered by the court? This approach derives, no doubt, from the legal concept of “presumption of continuance”, according to which, once it has been proved that someone is incompetent, or lacks capacity, this state is presumed to continue until the contrary is formally proved. (“Assessment of Mental Capacity”, Law Society/British Medical Association, 1995, p 13). Whilst such a presumption may have some legal value it is pernicious in situations of medical care, particularly in cases of serious illness, when capacity may fluctuate widely over a very short period of time. In at least one case in America a patient crying out for food or a drink was refused it on the grounds that she had not regained (legal) capacity to countermand her earlier advance instructions.

No legal presumption should be permitted to interfere with a contemporaneous ability of the patient to change his mind and to revoke the contents of a living will or the power of an attorney (at least in matters of health care) with respect to the immediate questions of treatment. 20(1) seems to envisage the possibility of sudden change affecting the power of deputies and the same should apply equally to attorneys.

10(4)(“d”?) For the protection of the patient, and indeed that of the doctors and nurses involved, a restriction should be added to this section to the effect that no attorney would have the power to give “a direction that a person responsible for P’s health care allow a different person to take over that responsibility” (as specified for a deputy, at 17 (1)(e)). Otherwise, where there is a disagreement over P’s best interests, the possibility arises of repetitive “shopping around” until a sufficiently compliant doctor is found.

12. *Revocation of lasting powers of attorney etc*

12(2). The same difficulty (as for 10 (4)(a)) applies in this section. Whereas 12(2) seems to suggest it would be comparatively easy to revoke a power previously given, Schedule 3, Part 4, 14(1)(a) and (c) indicates it would be extremely difficult, whether in whole or in part, and certainly not at all quick. In medical matters it must be possible to withdraw any power previously granted at very short notice.

17. *Section 16 powers: personal welfare*

No court, attorney, or deputy should be permitted to refuse “basic care” (see, for example, the very minimal list in Law Commission document “Mental Incapacity” (Law Com No 231) 1995)). Basic care should include not only bodily cleanliness, the alleviation of pain and distress and the offering of direct oral nutrition and hydration, but also the continuation of ordinary treatment (eg insulin for a diabetic and, in most cases, the assisted giving of food and fluid for one who cannot swallow). See also at 24 (5).

23. *Advance decisions to refuse treatment: general*

There is no specification in the Bill of what, if any, formalities are required to establish the legal validity of an advance decision, [written signature, actual date, witnesses' confirmation of patients' capacity at the time, confirmation that they have fully understood what it entails, etc] nor of how it should be formally registered or how long it should be deemed to remain valid. The requirements for advance directives, giving—as they do—power over life and death, should be no less stringent than those for the making of a will.

23(1)(a) Whereas the specific refusal of a particular treatment may be considered acceptable, “blanket” refusals of all (or multiple) medical treatments [even in various “postulated” circumstances] are not. This is because such a refusal is inevitably cast too widely for the patient to have been able to envisage all the possibilities for future situations or for future possible treatments (see 24(4)(c)). Such refusals fall far short of any semblance of properly informed consent—as required (and expected) for the capable: why should the incapable be any less fairly treated?

23(2) The phrase “in broad terms and non-scientific language” is derived from the requirements of obtaining proper consent to the acceptance of medical treatment. However, this is quite inadequate as an expression of sufficient understanding when it comes to refusals of treatment, particularly where these may well be life saving and a refusal may lead to death or serious handicap.

23(3) It is highly desirable that the patient should be able to withdraw an advance directive at any time and with the least possible formality. This should allow for the “resumption” (*sic*) of capacity on the balance of probabilities (as opposed to “beyond reasonable doubt” for the establishment of incapacity)—and in the face of any “presumption of continuance”. In other words the retraction of an advance directive must be made easier than the implementation (execution) of one. Otherwise the possibility exists of a patient who has recovered competence being overruled by a blind insistence on the implementation of such a directive (by the law, by a deputy or by an attorney (acting under lasting powers of attorney)).

24. *Validity and applicability of advance decisions*

24(2)(b) I believe it would be wrong for a donee (attorney) to be able to be given power to override a properly established advance decision (see section 23)—unless, of course, the advance decision has been withdrawn.

24(2)(c) It is hard to see how an action could be inconsistent with an advance directive, still less how evidence of it would be adduced (by whom?) or proven at the time of implementing the relevant “instruction”.

24(4)(a–c) These requirements are very important in any case of advance decisions. Otherwise wide and vague interpretations, that could be lethally dangerous, might be possible.

24(5) No advance directive should be allowed to refuse basic care (see at 10 and 17). If an advance directive is to be allowed to refuse life-sustaining treatment it must specify in precise terms which such treatment is being refused and not seek to encompass “life-sustaining” treatments in general.

25(3) This clause should be reworded to mean (as I assume it intends) that any claim of “reasonable doubt” applies to the applicability or otherwise of the terms of an advance directive in a particular case and not to the speculative existence, or otherwise, of an unseen advance directive. If the latter were permissible it could be very easily subject to abuse.

26–29 *Excluded decisions*

The Bill does not seem to address the issue of consent to sterilisation, to termination of pregnancy or to taking part in a research project (most particularly non-therapeutic research which by definition does not benefit the patient). I believe the latter should never be permitted, but all these matters should at least be reserved to a court and not lie within the powers of deputies or attorneys. It would also be totally inappropriate for a court, deputy or attorney to be given power to make an “advance directive” for the patient.

August 2003

129. Memorandum from the Disability Right Commission (MIB 1057)

INTRODUCTION

1. *Background*

1.1 The Disability Rights Commission (DRC) was created by the Disability Rights Commission Act (DRCA) 1999. Section II of the DRCA imposes the following duties on the Commission:

- To work towards the elimination of discrimination against disabled persons;
- To promote the equalisation of opportunities for disabled persons;

- To take such steps as is considered appropriate with a view to encouraging good practice in the treatment of disabled persons; and
- To keep under review the workings of the Disability Discrimination Act (DDA) 1995 and this Act.

1.2 The Commission has given itself the mission of seeking to achieve a society in which all disabled people can participate as equal citizens.

2. *Scope of the response*

2.1 The DRC's response is concerned with the interests of disabled people who could be subject to the provisions in the Bill including:

- Disabled people who may lack capacity to make decisions at some times and/or who may lack capacity to make some decisions, including for example mental health service users and survivors and people with learning difficulties.
- Disabled people who may be wrongly judged to lack capacity to make decisions due to others' incorrect perceptions of disability.
- Disabled people with different methods of communication who may be wrongly judged to lack capacity to make decisions.

2.2 The DRC also notes that it is vital that the same principles should underpin the Incapacity Bill and any proposed mental health legislation: in particular, both Bills should ensure that no one who is capable of making a decision about their treatment should be given treatment without their consent.

2.3 We welcome this opportunity to comment on the Bill and would be pleased to clarify any points contained in this response. However the short timescale allowed for written responses (over the summer period when many people are on holiday) has not allowed us to consult stakeholders in the depth that we should have liked.

2.4 We have raised concerns about the terms "capacity" and "best interests" and whether these can be defined on the face of the Bill. We will be holding a seminar on 22 October to enable stakeholders to discuss these issues further.

3. *DRC response to the draft Mental Incapacity Bill*

3.1 Introduction

3.1.1 Legislation to clarify who can and who cannot make decisions regarding personal welfare and health decisions (as well as financial ones) for someone who lacks capacity, has been lobbied for over a number of years and is to be welcomed. The Commission believes that there is a need to clarify law to underpin decision-making when someone is temporarily or permanently unable to take a particular decision, and to put in place robust safeguards to maximise autonomy.

3.1.2 The Commission will however resist any attempt to take away a person's right to make decisions on their own behalf and to give that right to others, where they are able to make those decisions. It will be essential to ensure that disabled people are given maximum support to make decisions themselves.

3.1.3 The Bill addresses a complex area and needs to provide clarity on decision making for a wide range of people with different types of impairments, in different situations. For example, a person with a learning difficulty who is in hospital receiving intensive care must be given every opportunity to make a fully informed decision about their treatment; someone with a fluctuating mental health problem needs to know they will receive support they have specified in advance, or support specified by a person of their choosing, if they become temporarily incapable of making decisions for themselves.

3.1.4 The underlying philosophy should be that support for decision-making is available but only at points where it is needed. It should not be forgotten that many people with learning difficulties and mental health problems are leading independent lives today who 20 years ago would have been considered unable to do so. Whether we consider people "capable" depends on the context in which people are living and the attitudes of those around them. It is all too easy for well-meaning professionals to take over decisions, to provide "help" with decision-making when it is not required. When people are "helped" in this way they do not gain the confidence and skills to take decisions themselves—which can confirm the view that they are "incapable". This happened on a large scale through institutionalisation; but can also occur in community settings. The belief that people are "incapable" in effect becomes a self-fulfilling prophecy. The DRC believes that a success measure for the proposed legislation would be delivery of greater (not fewer) opportunities for people with mental impairments to take their own decisions.

3.1.5 In pursuance of this vision we would want to protect a person's right to make decisions irrespective of whether others might believe them to be "wrong". There should not be an assumption that disabled people need particular protection from risk. They should be expected to take risks in the same way that all citizens do. There should be a level playing field allowing disabled people the same level of freedom to make

decisions, with their attendant risks, as other citizens. We would also want disabled people, like their fellow citizens, to have the full protection of the law if they were exposed to unnecessary risk or had been victims of crime.

3.1.6 The underlying principles as stated in the Bill are therefore welcomed:

- Capacity must be assessed against a particular decision at the material time.
- A person must be assumed to have capacity unless it is established that he lacks capacity.
- A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
- A person is not to be treated as incapable of making a decision unless all practicable steps to help him do so have been taken without success.
- The need to permit and encourage him to participate, or to improve his ability to take part, as fully as possible in any act done for and any decision affecting him.

3.2 The aim of the draft Bill

3.2.1 “The Mental Incapacity Bill aims to provide a clear, simple, informal system that will ensure people can maintain a maximum level of autonomy. People would be able to choose someone who can make decisions for them when they cannot do so themselves. And there would be clear rules on how decisions should be taken, making sure that vulnerable people were not left open to abuse.” Lord Filkin CBE Parliamentary Under-Secretary at the Department for Constitutional Affairs.

3.2.2 For many people the Bill will achieve what it sets out to do. This includes, for example, some people with mental health problems who run their own lives successfully when well but when in crisis are sometimes unable to do so; they will be able to nominate someone to make daily decisions about their lives on their behalf.

3.2.3 However for some disabled people, particularly those with learning difficulties and those in “closed” situations, there is a clear danger that the “general authority” far from enabling choice, control and autonomy, will make it easier to override their wishes.

3.3 The general authority

3.3.1 The general authority makes it lawful to act for someone who lacks capacity where it is reasonable for the person taking the action to do so and the act is in the person’s best interests. No formal powers are necessary. It is envisaged that “Most of the day to day care of adults who lack capacity will take place under the general authority with no need for any formal decision-making authority.”

3.3.2 Historically disabled people have experienced decisions being made for them by others inappropriately (sometimes well-intentioned, sometimes not), and are rightly concerned that the general authority, instead of providing protection from what currently happens (sometimes illegally), will in fact simply legalise such actions.

3.3.3 While it is recognised that the provisions in the Bill would simplify the job of carers and assist them in dealing with day-to-day healthcare and other problems and also provide safeguards for professionals, such as doctors, nurses and social workers, the rights of the individual must be paramount.

3.3.4 The general authority, places all responsibility on the carer or professional to judge whether someone lacks capacity to make a decision, and then to decide what is in their best interests. It relies totally on the understanding and goodwill of the carer or professional, sometimes with no independent support for the disabled person. It is therefore open to misuse and abuse, both intentional and unintentional. It offers little protection for the rights of people who may have difficulty making or communicating decisions. In particular the safeguard for the decision-maker that “there is sufficient compliance of acting in the persons best interests if the decision-maker reasonably believes that what he or decides is in the best interests of the person concerned” is extremely weak in protecting the disabled person. The DRC believes that a stronger safeguard is needed in the form of a right to independent advocacy (see below). This would both assist the individual in asserting his or her wishes wherever possible and act as a check on the professional’s or carer’s judgment where the person could not express any view. Where the advocate and carer/professional could not agree the matter should be referred to the Court.

3.4 Definition of Capacity and best interests

3.4.1 The Bill lays down some general principles regarding capacity, and some criteria and those people who should be consulted, in deciding best interests.

3.4.2 The Bill does not address the current lack of a clear legal definition of who does, and who does not, have capacity to make day-to-day decisions. To safeguard disabled people from being wrongly deemed to lack capacity (either in some instances or overall, whether deliberately or unintentionally) what “capacity” means needs to be defined as clearly as possible.

3.4.3 The Bill includes a list of criteria for use when considering what is in the best interests of the person concerned but there is no clear definition of what “best interests” means or how they are to be decided. Even in cases where the disabled person has a carer who wishes to maximise their decision-making, the terms “best interests” and “capacity” are not sufficiently defined to aid them.

3.4.4 The lack of clarity surrounding these issues has caused considerable problems for disabled people in access to health services for a number of years up to the present. Do Not Resuscitate (DNR) notices have been posted on disabled people’s notes without consultation as the consultant has decided it is in their “best interests”.

3.4.5 What is meant by “capacity” and “best interests” should be addressed on the face of the Bill as far as is practicable, but so as not to restrict flexibility in relation to the range of situations the person might be in; and then reinforced and developed in the codes of practice. This will be crucial in achieving the aims of the Bill.

3.5 Advance Decisions to Refuse Treatment

3.5.1 Advance decisions to refuse treatment may be used by people who wish to plan for a future loss of capacity and who wish to make clear what treatments they would wish not to receive. An advance decision must be made whilst the person has capacity.

3.5.2 There are many sound arguments in favour of advance statements. For example Mind has welcomed, “The clear recognition that people will be able to state in advance which treatments they do not wish to have should they lose capacity (eg if someone has experienced bad side-effects from an anti-depressant in the past).”

3.5.3 However there have also been concerns raised regarding people in “closed” relationships, where the disabled person can be vulnerable to coercion by others who have an interest in the outcome, for example, who would benefit from the death of the disabled person.

3.5.4 Baroness Findlay of Llanduff quotes an example from her clinical practice.

“A lady aged 59 was very ill. Her family appeared to be very concerned about her pain and constantly asked for her diamorphine to be increased. However, we remained unconvinced that her pain was really that severe. In fact, the patient declined increasing doses of diamorphine. Her 60th birthday arrived and was passed with minimal celebration, after which the family visited very little. She became depressed and spoke to one of the night nurses, explaining that the problem was that on her 60th birthday, her fixed-term life insurance policy expired. The family would not now inherit what they thought they would if she had died, and if her drugs been duly increased.”

3.5.5 The draft Bill does not contain sufficient safeguards to ensure that disabled people are not coerced into making advance statements.

3.5.6 If it is possible to legislate sufficient safeguards and Advance Directives are given legal status, then they should include the right to say what positive treatment the disabled person does wish to be taken to sustain their life in the event of accident or illness, for example use of artificial ventilation. This could have a positive effect on safeguarding disabled people’s lives. At present the whole debate on advanced directives is biased towards refusal—not acceptance—of treatment. This is an unacceptable bias.

3.5.7 There is a further risk in advance directives: that someone who has never experienced disability, who has incomplete understanding and who is influenced by negative perceptions of what life with a disability might be like, could decide that—were they to become disabled and incapable of making a decision eg develop dementia or experience brain injury—they would wish to have no treatment. There is a major challenge in ensuring that individuals are provided with substantial, unbiased information before making advance statements concerning conditions that they have not experienced. It is much more difficult for them to know in advance what they might wish than it is, say, for someone with a fluctuating mental health condition who already knows which treatments they do and do not want when their condition recurs.

3.6 Independent advocacy and communication needs

3.6.1 The draft Bill does not contain sufficient safeguards for some people (especially those in “closed” situations) to ensure that they are able to make decisions for themselves wherever possible, nor does it provide a proper mechanism to support people to make their own decisions or make their wishes known.

3.6.2 Historically, many disabled people have been excluded from making decisions or have had their wishes overridden. Sometimes this happens inadvertently but, unfortunately, sometimes it is intentional. Other disabled people can be deemed to lack capacity simply because they have difficulty communicating their wishes.

3.6.3 A particularly important safeguard and support that has not been included in the Bill is the right to independent advocacy. This would: ensure that disabled people are not wrongly deemed to lack capacity, enable disabled people wherever possible to make decisions and be involved in mutual decision-making, ensure their “best interests” are at the heart of decisions when they lack capacity, and ensure they are not open to coercion.

3.6.4 It is difficult to envisage how the Bill can achieve its aims for all disabled people without a right to advocacy. For example the Bill states that “all practicable steps must be taken to help the person make the decision before they can be regarded as lacking the capacity to make that decision”. This is often best achieved through independent advocacy (sometimes simply to aid communication).

3.6.5 It is essential that disabled people have access to independent advocacy when they need it, to enable them to make choices for themselves. In particular, it is essential at important points of the process eg when making advanced statements, and when the Court is considering whether the person has capacity to make their own decisions, when capacity is being assessed in relation to a major life changing decision, when appointing an attorney to act on their behalf, and when appointing a deputy in the case of disputes.

3.6.6 Access to independent advocacy is the key safeguard that would strengthen the right of individuals to make decisions for themselves. The General Authority, without a right to advocacy, could leave this right open to threat.

3.7 Consistency with proposed mental health legislation

3.7.1 The DRC believes it is vital that incapacity law and mental health law should be based on consistent principles. In particular no one who has “capacity” to take decisions about treatment should be given treatment without consent. Please see the attached DRC response to the Draft Mental Health Bill 2002 for a fuller explanation of these arguments and their implications.

3.8 General issues

3.8.1 The Bill will require sufficient funding to successfully achieve its aims. The DRC will want to see as a prerequisite, a legislated, funded right to appropriate support to enable disabled people to make their own decisions, and protection from having decisions imposed upon them. This will include: access to independent advocacy, effective dissemination of information on the existence of the legislation and its provisions (for disabled people, carers and professionals), and access to communication support. There must be readily available and accessible information for disabled people, on their rights and where to get help.

3.8.2 The Codes of Practice will be crucial to ensuring that the law protects those it is intended to protect whilst not undermining the autonomy of others. Sufficient time and outreach must be devoted to consultation on the Codes to allow proper consideration of the implications.

3.8.3 In addition, the working of the legislation will require in-depth monitoring to disclose whether it is effectively enabling the autonomy that has been promised.

September 2003

130. Memorandum from Mind (MIB 1060)

Mind is the leading mental health charity and works for a better life for everyone with experience of mental distress by:

- Advancing the views, needs and ambitions of people with experience of mental distress.
- Promoting inclusion through challenging discrimination.
- Influencing policy through campaigning and education.
- Inspiring the development of quality services which reflect expressed need and diversity.
- Achieving equal civil and legal rights through campaigning and education.

1. INTRODUCTION

Mind is a member of the Making Decisions Alliance and supports the general thrust of the response submitted on behalf of the Alliance. We therefore confine our response to some additional issues, which in our view are particularly relevant for people with mental health problems.

2. DETERMINING BEST INTERESTS

Central to the Bill is a concept of best interests. The Bill states that “Regard must be had” to the individual’s past and present wishes and feelings. However this fails to give adequate weight to the individual’s past and present wishes and feelings, or to the views of any person appointed by the individual to act on their behalf. Often the past and present wishes and feelings of a person diagnosed with a mental health problem are easily ascertainable, as they may have lost capacity only recently or have fluctuating capacity.

We would also like to see the list of factors to take into account in determining best interests to be expanded in line with the Scottish Adults with incapacity Act to emphasise protecting the individual from on overzealous use of the power and to enhance the principle of autonomy.

In our view there should be

- (a) “a duty to take account of” these wishes and feelings;
- (b) more weight should be given to the views of a person who has been specifically nominated to be consulted (for instance under the Mental Health Act) or appointed as an attorney under a Lasting Power of Attorney; and
- (c) the list of factors should be those in the Adults with Incapacity Act.

3. MEDICAL TREATMENT (WHERE THE PATIENT RESISTS).

The general authority

This covers the right to consent to and to refuse medical treatment on the individual’s behalf (subject to an advance decision). However nothing in the Act authorises anyone to give a patient medical treatment for mental disorder, or to consent to a patient being given medical treatment for mental disorder, when this is governed by Part IV of the Mental Health Act 1983, that is for people who have already been sectioned.

The general authority does not authorise a person—

“to use, or threaten to use, force to secure the doing of an act which P resists, or to restrict P’s liberty of movement whether or not P resists, unless the person reasonably believe that it is necessary to do so to avert a substantial risk of significant harm to P”.

We are concerned about the situation for those who are not subject to the compulsory treatment provisions under the Mental Health Act.

People with mental health problems should not be subject to confinement or unregulated coercion, force, or potentially dangerous treatments for their mental health problems without adequate safeguards as would apply under mental health legislation. In our response to the Law Commission in 1995 Mind stated that we believed that a person should not be confined or forced to act “unless such action is essential to prevent an immediate risk of serious physical harm to that person or others”. It follows that we would recommend narrowing the provisions of the current Bill to require an immediate risk and also to limit it to physical harm. Outside that situation we believe that there should be no power to administer medical treatment for a person’s medical condition when they are resisting treatment.

Where a patient gives another (the donee) a power to make medical decisions on their behalf the situation may seem a little different. If a person nominates someone they trust to take care of their health in the event of their incapacity they may prefer that this person has the power (either under an LPA or by advance directive) to decide whether treatment should be given in the face of their opposition than for them to be subject to the control of medical professionals under compulsory powers. The Draft Mental Health Bill limits the clinical supervisor’s power to impose treatment on resisting patients who lack capacity to a situation of “urgency”.

There needs to be a balance between respect for the patient’s choice and for the patient’s safety. There may be room for some interventions (for instance the routine administration of medication) that could occur with a second opinion or a court order rather than through compulsory powers. There is also a distinction between a situation where the person without capacity is reluctant to take regular prescribed medication and one where real force must be administered. We acknowledge that it will require some consultation and further thought to draft appropriate criteria but the Code of Practice could be used to give examples. In our view the Bill as drafted is too broad.

4. MEDICAL TREATMENT—SAFEGUARDS

Even where the person without capacity is not resisting treatment we believe that there should be a second medical opinion in the same circumstances as one is required under the Mental Health Act (long-term medication, ECT). Extra safeguards should exist for more invasive or controversial procedures (including but not limited to invasive treatments for mental disorder).

5. ASSESSMENT OF CAPACITY

No provision is made for identifying the person responsible for determining whether P has capacity at the relevant time. If a person is sectioned or has a diagnosis of mental disorder we believe there may be problems if it is solely up to the treating psychiatrist to determine capacity.

There is a risk in relation to treatment for mental disorder that a person will be assessed as not having capacity when they are refusing treatment and someone else may consent on their behalf, or a LPA or the general authority will be used. Again this would bring people outside of the safety structure as the Bill is currently drafted.

We believe that there needs to be clearer guidance about who assesses capacity and when. This will need to be clarified in the Code of Practice.

In addition, it may be necessary to be more explicit in the Code of practice that “irrational” decisions will not necessarily indicate a lack of capacity. The Bill says that a person is entitled to make unwise decisions, but we do not believe this goes far enough. There may be a difference in substance between a lack of wisdom and what may be seen as irrationality. In particular, decisions based on unshared perception should not lead to a presumption of incapacity.

No provision appears to be made for appealing a medical capacity/incapacity decision. Complexity or difficulties in obtaining public funding may mean that in fact capacity decisions continue to be made by psychiatrists treating P (or RMOs) and this would constitute a disincentive to appealing such decisions. This is particularly significant, as the validity of advance decisions will depend upon the assessment of capacity. We are concerned to ensure that the opportunities for disregarding such decisions are minimised. It may be worth considering whether there needs to be a procedure for independent second opinion doctors and recording/certification in relation to assessment of capacity as well as treatment decisions. (cf. SOADs under current MHA).

The Bill arguably leaves uncertainty as to when independent scrutiny of capacity/incapacity decisions may occur. There is provision for the Court to exercise a power to call for reports and a Medical Visitor can carry out a medical examination of P in private. But this only occurs if the case comes to court, and even then, not always. Rather, it is only if the Court requires, and the circumstances when this may happen are left open. It could be commented that the Bill makes more comprehensive provision for protection of attorneys from liability! (eg Part 5, Schedule 3).

6. ADVANCE DECISIONS

The Bill makes specific provisions for the recognition and enforcement of advance refusals to accept treatment.

Although we welcome the inclusion of advance decisions no direct reference is made to the relationship between Advance Decisions and the Mental Health Act. We are disappointed that an individual cannot use an advance decision to refuse treatment authorised under the compulsory treatment provisions of the Mental Health Act. This is a development that Mind wished to be included and would have enhanced the other provisions concerned with bodily integrity as protected by the European Convention on Human Rights. This would have been in line with our view that treatment under mental health legislation should be also be based on incapacity and best interests.

We understand the reasons that positive advance decisions are not included in the Bill. However, we do not see why expressions of preference should not be taken into account when they relate to method rather than result. This is particularly relevant for people with fluctuating capacity, who may be able to plan for periods of incapacity and may well have learned from past experiences. If a person knows that a particular medication or treatment works for them then we believe that they should be able to record that fact. Because the Bill is not robust enough in relation to the duty to take wishes and feelings into account we believe that it would be helpful to allow people to express their wishes in advance in limited circumstances. Further more many features of an advance decision could cover matters other than medication.

7. CODES OF PRACTICE

The binding power of the Code could be strengthened on the face of the Bill—especially since the Court of Appeal decision in relation to the Mental Health Act Code of Practice. Why say that the duty is merely to “have regard to” the Code? We believe that it will be unlawful for a public body to depart from a Code of Practice unless there are compelling circumstances in an individual case. This is particularly so where the Code relates to rights protected under the European Convention (as most of them will under Art 8—right to respect for private and family life). The group protected by the proposed legislation is a vulnerable one and in many cases they will find it hard to bring legal proceedings. The status of the Codes of Practice should be upgraded and simplified so as to confer greater immediate protection from decisions that may infringe human rights. This in turn could reduce the need to go to court for the purpose of determining when the Code may be departed from.

Related to this point is the fact that there is no obvious sanction for not complying with the legislation. Because of the generality of the Bill we suspect that it will actually be incredibly difficult to challenge decisions made under it. People concerned with the care of a person without capacity will retain a huge amount of discretion and there will be a lot left to subjective determination. The provisions about assessment and treatment, and the status of the Codes, should be much more robust if they are to afford any real protection to people without mental capacity, or guidance to those involved with their care.

8. ADVOCACY

Mind is in favour of advocates being available to anyone who would find them helpful. However, we believe that there are important differences between mental health legislation and incapacity legislation. Mental health law provides the power to detain and treat a person against their express wishes, and regardless of their capacity or “best interests”. For this reason we feel much more strongly about their involvement in such decisions.

Where advocates are available we believe that they should have some status so that what they say on behalf of their client cannot easily be disregarded. Otherwise there is a risk that their involvement will merely be tokenism. If advocates have a recognised status they will also have a corresponding duty, which might involve greater regulation and training. It should also be acknowledged that access to advocates is not a substitute for access to legal advice and redress.

September 2003

131. Memorandum from the National Autistic Society (MIB 1061)

OVERVIEW

1. The National Autistic Society (NAS) is the leading charity for people with autism spectrum disorders (ASD) in the UK. It has a membership of over 12,000, a network of 60 branches, and 60 affiliated organisations in the autism field. The NAS exists to champion the rights and interests of all people with autism spectrum disorders and to ensure that they and their families receive quality services, appropriate to their needs. There are approximately 520,000 people with autism spectrum disorders in the UK.

2. The NAS welcomes the opportunity to comment on the draft Mental Incapacity Bill. However, we would urge the Committee to recommend that the title should be changes to the Mental Capacity Bill. This would underpin the underlying principle of the Bill that there is a presumption of capacity unless it is established that the person lacks capacity.

3. The NAS is a core member of the Making Decisions Alliance (MDA), a consortium of 27 organisations and groups working with people who may have difficulty making or communicating decisions. The NAS mirrors the views of the MDA on the draft Mental Incapacity Bill but would also add the following commentary that relates specifically to adults with autistic spectrum disorders (ASD).

KEY PRINCIPLES

Lack of Capacity relates to each decision to be taken

4. The NAS agrees that the starting point should always be that the person has capacity and the Bill states that “all practicable steps” must be taken to help the person make the decision before they can be regarded as lacking the capacity to make that decision (Clauses 2,3). It is particularly true that adults with ASD are able to make some decisions but not others; therefore it is important that each decision should be addressed on the person’s capacity to make a decision on a matter at that point in time.

5. Difficulties may arise in assessing the capacity of adults with autism because of the nature of the communication impairments associated with the condition. Some people with autistic spectrum disorder have an average or above average IQ level but because of their autism still have enormous difficulties with communicating their needs and wishes. Therefore, it is essential that any assessment of capacity must include a professional with the knowledge and experience of autism spectrum disorders, including, where relevant, language/communication professionals, psychiatrists and clinical psychologists should a dispute requiring court intervention arise.

MECHANISMS

Single Orders of the Court

6. The NAS welcomes the concept of Single Orders of the Court within the Bill. Although Single Orders of the Court may be deemed an extra bureaucratic hurdle to overcome they can also act as an acceptable meeting point between acting too loosely under the General Authority and applying to become a Court Appointed Deputy (see below).

The New Court of Protection

7. The scope and influence of the new Court of Protection will help to build and maintain expertise in matters arising to adults with impaired capacity. The NAS are also looking for a commitment that all those working for the Court will build up expertise in autism, so that evidence presented as to whether a person with an autistic spectrum disorder lacks capacity can be effectively evaluated.

GENERAL AUTHORITY

8. The NAS has reservations about the scope of the General Authority. A primary concern is that the General Authority may undermine the presumption of capacity set out in Section 3 of the Bill. Fluctuating capacity is particularly relevant in adults with ASD depending on their physical environment, mood and control of a specific situation. It is therefore paramount that “all practicable steps” are taken to ensure that a person can understand and make a decision including waiting until the person is calm and able to communicate their wishes. The General Authority must take fluctuating capacity into consideration and respect the presumption that many adults with ASD are able to make decisions, both with and without support.

9. Given the difficulties in accurately assessing capacity for adults with ASD the NAS believes that greater checks on the application of the General Authority will be necessary. In particular, the Scrutiny Committee should ask the Government to clarify on the face of the Bill that carers who expect to take a wide range of decisions across an indefinite period should have it noted (eg in a care plan, at a case conference or review) that decisions were being made under the General Authority.

COURT APPOINTED DEPUTIES

10. The NAS is concerned that the Court of Protection should only appoint a Deputy when an independent assessment of capacity (including an autism expert) to take a particular decision has been made. Also, the appointment of a Deputy is a key moment when we believe a right to access independent advocacy should be triggered.

OMISSIONS

Appointeeship

12. The NAS strongly supports the MDA’s call for appointeeships to be included in the Bill. A large percentage of adults with autistic spectrum disorders receive state benefits and as the Bill sets out to safeguard adults with impaired capacity the NAS believes that appointees should be required to act in *a person’s best interests* when considering how financial affairs are handled.

Advocacy—the need for supported decision-making

13. The publication of the Mental Incapacity Bill is an ideal opportunity for the Government to fund advocacy support for adults with complex communication disorders such as ASD in order to support them to make decisions. The NAS believes that the involvement of an independent advocate should be regarded as standard practice when a carer is seeking to demonstrate that “all practicable steps” have been taken to help a person make their own decision (clause 2).

14. Expanding the capacity of independent advocacy organisations to work with people with ASD will be necessary to make this a reality. It is clear despite *Valuing People*¹³⁵ adults with ASD are still missing out on advocacy support. Adults with ASD would benefit from advocacy support with housing, assistance in the transition to adult services, employment, assistance with social integration and access to health services.

15. *Autism: Rights in Reality* (2003)¹³⁶ found that only 11% of adults with ASD had ever used an independent advocate, despite the majority wanting to access this support. Carers often play an important part in supporting people with ASD but continuing reliance on their families may inhibit independence. This is why access to advocacy can be important in supporting people with autism to have a greater degree of independence.

¹³⁵ Broach S. et al (2003) *Autism: Rights in Reality*. London: National Autistic Society.

¹³⁶ Department of Health (2001) *Valuing People: a new strategy for learning disability for the 21st Century*. London: Department of Health.

16. Advocates for adults with ASD can be involved to support decision-making because of the difficulties of communication, choice and expressing their wishes experienced by this group. It is sometimes the case that advocates may only be able support a few people with ASD at any one time. Therefore, the proposals in the draft Mental Health Bill for paid casework advocates to support a number of clients would be unlikely to benefit adults with ASD if applied to this Bill. It is also important to emphasise how vital it is for advocates to fully understand the communication difficulties and all other aspects of autistic spectrum disorders in order to advocate successfully for an adult with ASD. However, the benefits of involving an advocate, both in terms of quality of life and the financial savings that may result from continuing independence can be substantial.

17. The NAS urges the Department for Constitutional Affairs, Department of Health and local authorities to work together in order to fund independent advocacy organisations to include people with ASD within their client group.

August 2003

132. Memorandum from Mrs Eileen McManus (MIB 1073)

1. Having worked in the NHS for over 40 years, both as a nurse and as a Chartered Physiotherapist, I am making this submission because the Draft Mental Incapacity Bill raises alarm in me and, I am sure, terror, in elderly, disabled or mentally infirm patients and/or their carers.

In any situation when working with people it is essential to have their confidence and co-operation. This is particularly necessary when helping people recover from illness, accidents or disabling events. If this Bill becomes law it will make it impossible for patients and their relations to trust that their doctors, nurses and therapists have their welfare at heart. Not a good basis for delivering healthcare.

BEST INTERESTS

2. Normally doctors acting in the patients "best interests" will take account only of the basic tenets of medicine: to save life, minimise suffering and restore health. However the Mental Incapacity Bill defines "best interests" as the wishes and feelings of the patient. None of us know how we will feel about our life ahead of the life-threatening or disabling event. Decisions made when younger and healthier should not be binding for the rest of life. Being killed by any means can never be in the patient's best interest.

LASTING POWER OF ATTORNEY

3. This will allow the person appointed power, not only over financial matters but also over life and death if the patient is deemed to have lost the capacity to make their own decisions. This is so obviously open to abuse, particularly if the appointee can benefit in any way from the patient's death and has no built in safeguard for the patient as the very people who should be protecting the patient's life, their doctors and nurses, have to listen to the person with the power of attorney. People suffering from confusion but otherwise fit could have food and water withheld from them on the grounds that they had no quality of life. This is a judgement nobody can make about another.

HUMAN RIGHTS

4. Surely the provisions in this bill are totally incompatible with the European Convention on Human Rights? In particular, the Bill's recognition and implementation of advance refusal of treatment. In no other situation is "hearsay evidence" allowed but statements made in the past, under very different circumstances, before unqualified or even biased people will be deemed to be sacrosanct if this bill becomes law.

5. On a personal note, as a very young nurse I helped care for a young man paralysed totally from the neck down after a car crash the day before his wedding. Whilst being cared for he would beg to be allowed to die. His fiancée was at his bedside every day and he ranted at her to go and let him die. She stayed, and gradually with love, care and rehabilitation, he was able to sit in a wheelchair and she learnt how to manage. She never gave up on him; the physiotherapists worked hard with him but it was his fiancée's love and devotion that made the difference. The couple married and lived happy and fulfilled lives together. This was surely a better resolution than killing someone who was, quite naturally, depressed just after the accident when everything looked so bleak.

6. In conclusion I would like to point out that:

- (a) disabled people have the same right to life as everyone else;
- (b) food and water have the same purpose for disabled people as everyone else;
- (c) disabled people do not achieve "dignity" only in death;

- (d) we abolished the death penalty for murderers on the grounds that it was inhuman in a civilised society. How can we then allow the proposed killing of our vulnerable young, old and disabled? and
- (e) following World War II the Nazis were tried and convicted for the same practices that this bill proposes to allow.

August 2003

133. Memorandum from United Response (MIB 1111)

1. United Response is a member of the Making Decisions Alliance. As such we have been campaigning for legislation that would allow a person's capacity to make decisions to be considered outside of the Mental Health Act, and welcome the draft Mental Incapacity Bill. There are concerns that the broad definition of "Mental Disorder" contained in the draft Mental Health Act would mean that people with a learning disability could be detained even if they do not have a co-existing mental health problem. The Draft Bill could bring about a framework to provide medical treatment to people with learning disability outside the Mental Health Act. We have given our support to both the Alliance's and the Law Society's Submission. We give our support for calls for the draft legislation to be included in the Queen's Speech.

2. General

- i. We welcome the presumption of capacity and the proposed functional test. However, we are concerned that the title and the focus of the Bill, on the processes involved once a person is deemed to be lacking in capacity, do not properly reflect the underlying presumption. We believe it should be renamed the *Mental Capacity Bill*, and there should be more focus on the face of the Bill on support for a person in the decision-making process, ie on empowerment, advocacy and communication.
- ii. Successful implementation of the Bill will depend largely on the resources allocated to it, ie for staff training, (independent) advocacy and public information.
- iii. A key issue for people with learning disabilities is that the new legislation provides that people will not be prevented from making a decision simply because it is deemed to be unwise, some progress in ending the infantilisation of adults with learning disabilities.
- iv. Any reference to confinement/use of force in the draft Bill must only apply where a person's *immediate* safety is concerned, and must be followed up by an early assessment/care plan.

3. Advocacy

- i. The Bill says it puts the person with impaired capacity at the heart of the legislation, but does not set out mechanisms to achieve this. Without properly resourced advocacy some people who are able to make a particular decision could be wrongly assessed as unable to do so. In *Valuing People*, the Government says that Advocacy has a crucial role to play in supporting the choices of people with learning disabilities. The new draft Bill must recognise and strengthen this requirement rather than cut across it.
- ii. Advocacy should be available at the very least at the following stages:
 - (a) on assessment of capacity;
 - (b) when a major life changing decision is being taken;
 - (c) when a Court deputy is being appointed; a Lasting Power of Attorney is being setup or activated; when a single order of the court is being made;
 - (d) where there is a dispute—independent advocacy must be available to cover instances of conflict of interest between a person and their carer. For instance, the *General Authority* makes it lawful for any person to make a decision when caring for another person where they *reasonably believe* there is a lack of capacity (Clause 6). Without the involvement of an independent advocate, and with no requirement for capacity to be independently assessed, the GA may by default give statutory recognition to a "closed relationship" that will not be monitored by any third party, and may therefore be open to abuse.

Clause 6 goes on to make it lawful for a person to make a decision when caring for another person when "in all the circumstances it is *reasonable* for the person to do the act". Here again, access to independent advocacy may provide an important check on the *objective* reasonableness of the decision.

- iii. Moreover, effective advocacy brings with it not only protection and empowerment for the individual, but value for money for the Government. Achieving the decision in the best interests of a person, with which that person is content, at the outset might not only obviate the need to embark on a process of elimination until this is (or may never be) achieved, but also the need of recourse to a costly Appeals process.

4. *Scope of the General Authority*

- i. The Bill makes it clear that professionals will be able to operate under the General Authority and makes no distinction between a decision made on best interests by a carer or by a healthcare professional. We support MDA calls for a higher test of reasonableness for professional carers with single orders from the Court as a preference. More importantly, we feel that major life changing decisions, such as medical treatment and where a person should live, should be removed from the scope of the General Authority.
- ii. In addition to the Codes of Practice, there should be a public information campaign to inform all individuals [people with impaired capacity?] and carers of their rights and responsibilities. Without this, the subtle checks and balances set out in part 1 of the Bill may not be recognised.

5. *Assessment*

We would draw the Government's attention to the fact that the draft Bill does not explain how assessment will work in the context of this new legislation. We believe that this must be addressed. The literal interpretation of Clause 3 would require a continuous assessment of capacity each and every time that person was faced with a similar decision, but this would not be in the interests of the individual concerned, their carers or the relevant professionals. However, it would be equally unacceptable for the draft Bill to erode an individual's right to make their own decisions before capacity has been accurately and independently assessed. The importance of assessment in underpinning the work of the draft Bill cannot be overstated, and therefore "assessment" needs to be clearly defined, and the legal status of the Code of Practice for the guidance of persons assessing capacity needs to be clarified, along with any sanctions that will be applicable if the Code is breached or ignored.

6. *Lasting Power of Attorney*

Tighter controls should be placed on who can be appointed as donees to include those convicted of fraud or abuse of a previous LPA. In addition, consideration should be given as to whether CRB checks are appropriate. Donees should be fully informed of their rights and responsibilities and effectively monitored. The position of Care Staff acting without power of attorney (for example making financial decisions) needs to be considered for areas of conflict of interest.

7. *Court Appointed Deputies*

An independent assessment of capacity to take a particular decision should be carried out before a Deputy is appointed. This is the key moment when a right to access to independent advocacy should be triggered (see para 3iic). Deputies should not always be able to give consent to the withdrawal of treatment, rather there should be a requirement for a single order of the Court of Protection.

8. *Advance Directives/Advance Statements*

The Bill should provide for instances such as a severely disabled person who may wish to make an advance statement setting out their express wish that all reasonable steps should be taken to sustain their life in the event of accident or illness, regardless of any assumptions medical professionals may make about their quality of life.

9. *The New Bodies*

Court of Protection judges and staff will need training; *The Public Guardian* will have a vital role. The Bill needs to clarify what, if any, sanctions will be available to the PG if an individual is found to be acting outside the letter or spirit of the Bill.

10. *Omissions from the Bill*

We would like to suggest that the following also be considered within the scope of the draft Bill:

- Appointeeship, whereby a person can be given responsibility by eg the Benefits Agency for handling someone's welfare benefits because the Agency deems them incapable of doing it themselves, should be brought within the scope of the Bill. Appointees should be bound by the same Best Interest principles as Deputies or donees of LPAs.
- Adults at Risk, cross reference to regulations and guidance around vulnerable adults eg *No Secrets*.
- Participation in vital research by people who lack capacity.
- Data protection.

134. Memorandum from Dr S Conboy-Hill (MIB 1164)

Our team has broadly welcomed the Draft Bill, recognising that the current position is unacceptable, and acknowledges the effort and expertise that has gone into its production. We have also followed closely the proposals contained in the documents “Who Decides?” and “Making Decisions”, modifying our practice accordingly. The following comments are made with specific reference to adults with learning disabilities for whom the Draft Bill seems to make only token provision, its focus appearing to be largely on those who have had and then lost capacity or whose functional capacity fluctuates.

SUMMARY OF CONCERNS

1. Although learning disability is mentioned, there seems to be an assumption of initial capacity or history of capacity during which a person might make provision for incapacity or from which speculations about wishes and preferences might be derived by someone acting on their behalf.

2. This seems to be reinforced by the comment that a Deputy of the Court of Protection would be appointed where someone has not made, or has never been able to make, a Lasting Power of Attorney (LPA). There is no specific reference to learning disability, one of the few situations in which capacity may be questionable and/or graded throughout life, and so it is unclear how such a person might make an LPA or avoid being influenced into making an unwise appointment through expedient assumption of capacity (see below).

3. There is a requirement to assume capacity in the first instance. This may lead to expedient actions achieved through acquiescence, choice bias, lack of knowledge of alternatives in the recipient, power imbalance, and lack of assertiveness in the vulnerable adult.

4. Capacity has to be demonstrated at the time required. This is based on the notion that the necessary information does not have to be retained permanently but leads to the possibility that people lacking skills and crucially, time, to interview a client will be responsible for assessing capacity for example just prior to planned surgery.

5. The Bill is written as though the person has insight into the proceedings and complexities (see 1. above) and can at times, take some form of action. While this may be the case for some people, those with greater and lifelong impairments are unlikely to be in this position. People with good social presentation skills are particularly vulnerable to unfounded presumptions of capacity and many can be falsely believed to have capacity through unskilled interviewing.

6. Effective discharge of duty in the spirit of the Bill hinges on communication. Where people have no history of capacity through severe disability or whose capacity is graded and allows for competence in selected areas, skilled information giving and assessment of understanding are crucial. Bias, whether motivated or unconscious, is almost inevitable where there are vested interests and vulnerable adults need protection from the misguided or wilfully controlling actions of those who seek to represent them. Some user groups are particularly concerned about the role of families, saying that “parents have too much control already” and others want to draw the emphasis away from capacity *per se* to better access to information and to skilled advocacy.

7. The powers given by the General Authority to act reasonably, the LPA and the role of Court Appointed Deputy are potentially pervasive and carry serious consequences for the person without capacity. There seems to be an underlying assumption of goodwill and good intentions in those who seek to take these responsibilities and while this is likely to be the case in many situations, it will not be for some people. Similarly, good will and good intentions are not guarantees of good practice or competence. The Bill needs to make clear the lines of accountability that accompany these roles, to ensure that multidisciplinary teams have access to these lines in the event of dispute or concerns, and to make provision for advocacy against the advocate” where necessary.

8. People acting in the General Authority, LPA and Deputy roles are essentially operating as advocates but with considerable power over the individual without capacity. Advocacy is essential where there is vulnerability but the role itself requires an independence of thought, capacity for reflection and self-analysis, objectivity and separation of needs that, in therapists, can take many years of training to achieve. Experience of adults with profound learning disabilities and their advocates has included worrying representations of “wishes” where we could not be certain any existed. Combining this role with legal authorities would seem dangerous if not moderated by multidisciplinary scrutiny.

WITH SPECIFIC REFERENCE TO PEOPLE WITH LEARNING DISABILITIES

By definition, a person with a learning disability is someone who, from childhood, has had significant limitations of intellectual and social function such that at least 97.5% of the population would exceed their capabilities in these areas. Elsewhere described as having “arrested or incomplete development of mind”. Significant Learning Disability translates into IQ 69 or below (see DoH guidelines) or a range that, at its highest boundary, reaches IQ 73. Severe Learning Disability refers to the capabilities of people with an IQ of 55 or less (see British Psychological Society guidelines). Commonly people in the learning disability range have no discernible cause for their intellectual limitations. Possible explanations include normal distribution

(of IQ) and social and educational deprivation. Others have been impaired by genetic disorders such as Down's Syndrome or by brain trauma following infections, hypoxia, birth injury, or early head injury. Autistic Spectrum Disorder is over-represented in the learning disability range but is not necessarily associated with cognitive limitations. As a disorder of social behaviour and communication, there are implications for people with ASD whether this coexists with learning disability or not.

The Draft Bill proposes that carers and professionals working with people lacking capacity will be issued with guidelines about how to function within the Act when it becomes law and, critically, how to assess capacity. These guidelines have not yet been issued and consultation will be sought in their construction. We look forward to participating in this process.

PART 1 OF THE DRAFT BILL

This says that a person lacks capacity if, at the time a decision has to be made, the person is unable to make it due to a permanent or temporary disturbance in the functioning of the brain.

A person will be seen as unable to make the decision if:

- They cannot understand the information.
- They cannot retain the information.
- They cannot use the information as part of the decisionmaking process.
- They cannot communicate their decision.

The Bill requires all practicable steps to be taken to help the person make a decision and does not require long-term retention of the information for that decision to be valid. It also says that an "unwise" decision should not be treated as evidence of incapacity.

This is clearly crucial to identification of both capacity and incapacity and raises the following issues for adults with learning disabilities.

- An unwise decision may be an indication of poor understanding, lack of information or historical fears of a proposed course of action while assumption of capacity may result in both denial and imposition of services (through acquiescence and choice bias). At present we err on the side of caution where important decisions about health, finances, or living circumstances are to be made. Individuals are given information over time in appropriately constructed packages (discussion, booklets, drawings etc) and then interviewed for evidence of retention and understanding of this information. A variation of the Cognitive Interview is used for this purpose since it capitalises on contextual free-recall, non-leading questions and a structured component based on required knowledge.
- If a person's capacity to retain this information towards their decision is so short that it may have been lost between the interview and the date of the proposed action, it is difficult to see how capacity might be assessed by the professional requiring evidence of it before proceeding. At present a report is sent detailing the interview process and its conclusions but video evidence of the interview in the manner of Memorandum Of Good Practice (MOGP) Vulnerable Adult testimony may also be useful.

The commentary on clauses of the Draft Bill says that the ability to communicate a decision is a *residual category* only affecting a small number of people such as those with Locked in Syndrome. It seems to be assuming that someone who is able to communicate a decision will also be willing to do so and will make every effort to that end. In making this assumption, the commentary fails to recognise the particular difficulties of people with Autistic Spectrum Disorder, those who are electively mute, and people who will only communicate under particular and not easily replicable conditions. Failure to communicate a decision may not then, reflect lack of knowledge or understanding but if the decision cannot be accessed even with the assistance of people who know the individual and have the right skills, it is difficult to see how this category can be viewed as residual. Following from this, a further difficulty arises when we are asked to accept non-verbal expressions of consent or refusal of consent in place of a verbal expression. We would argue that this is reasonable where the information base upon which the person is making their decision can be assessed but otherwise is open to error. People may attend a hospital or clinic, offer their arm for blood tests, or sign a document for example through acquiescence and passivity. Similarly, they may refuse to attend, comply or cooperate through fear, past experiences, lack of information or poor understanding.

BEST INTERESTS

Ascertaining best interests in terms of preferences, wishes and feelings, and promoting a person's capacity to participate is a skilled job. Any person charged with this duty needs to be able to use techniques known to reduce informational contamination in gaining access to a person's views and to separate their own needs from those of the vulnerable adult.

GENERAL AUTHORITY

“It is lawful for any person to do an act when providing any form of care for another person (P) if . . . P lacks, or the person believes that P lacks, capacity in relation to the matter in question, and, in all the circumstances it is reasonable for the person to do the act.”

This may leave vulnerable adults open to abuse in situations where the carer, whether family, friend, partner or paid, is operating in relative isolation with an acquiescent adult whose ability to complain or to access people who might hear a complaint is limited. It also begs the question of what is “reasonable”.

Restrictions on the General Authority include “restriction of movement, whether or not P resists”. This may have implications for legitimate physical interventions designed to prevent or minimise harm to the person or others but is also open to the same abuse as the authority to act in that a person who “reasonably believes” that restriction is necessary to avert a “substantial risk of significant harm to P” may feel able to apply such a restriction. The Draft Bill does not mention of the use of restrictions to prevent harm to others. Learning disability services often provide for people whose behavioural repertoire includes physical aggression and self-harm. Many are not subject to any Section of the Mental Health Act and so methods of control and restraint often used in that context do not apply. Instead there are agreed protocols that specify last resort physical interventions in the interests of the safety of the individual and those around them. Failure in this Bill to provide for the safety of others could lead to serious difficulties in providing safe community services for adults with challenging behaviour.

LASTING POWERS OF ATTORNEY

An LPA can only be created by someone who has capacity to do so and in relation to themselves. It is not clear how a person with a learning disability might make an LPA, how capacity to do so might be assessed or, in fact, how one might gain informed consent to begin the process. While it is clear that many people have caring families who will do their best for a vulnerable adult, many others have families or carers whose actions are controlling at best and sometimes descend into the abusive and exploitative. Even those who would see themselves as having the best motivations regarding their vulnerable relative may be emotionally rather than objectively driven and can often fail to allow the freedoms to which other adults of similar capabilities have access. Some user groups are very concerned about the powers families may be given under this Bill and want to see more independent advocacy instead.

Those acting on behalf of a vulnerable adult should be open to scrutiny so that concerns can be raised. The Child Protection model may be of some help in establishing protocols particularly as some of the issues are similar and range from wilful abuse of a victim who is unable to report this to unwitting abuse of someone who is unaware that they are being abused but whose quality of life could be significantly improved if certain actions were to be changed.

In terms of Personal welfare, the LPA does not allow an individual “to use, or threaten to use, force to secure the doing of an act which P resists, or to restrict P’s liberty of movement whether or not P resists, unless . . . “P lacks, or the donee (the person appointed to the LPA) reasonably believes that P lacks, capacity in relation to the matter in question and, the donee reasonably believes that it is necessary to do the act in order to avert a substantial risk of significant harm to P . . .”

This carries the same risks as the General Authority to act reasonably but may be more likely to occur in private. Wherever matters of physical restriction may be thought advisable, risk assessments and clear protocols should be in place for determining all aspects of the intervention and reviewing its necessity. The Bill needs to make clear the duty of those with General Authority or LPA responsibilities to consult professionals and work within clear guidelines in such situations.

A further serious concern is the section of the Bill that seems to give those with LPA the authority to make decisions about a person’s personal welfare which extends to “giving or refusing consent to the carrying out or continuation of a treatment by a person providing health care for P . . . if P lacks capacity to give or refuse that consent”.

It does not extend to life-sustaining treatment unless there is provision within the LPA agreement about this but might be used to deny access to a variety of activities and treatments that are not life-sustaining but nevertheless valuable to the vulnerable adult. An example might be counselling or group work aimed at enabling the person to become more confident and assertive thereby making them less malleable to the person with LPA, or denial of contraceptive advice/treatment in accordance with the beliefs or preferences of the agent but not necessarily the vulnerable adult.

One wonders how the vulnerable person represents themselves if the carer does not see the potential for capacity or actively or unconsciously denies this.

These concerns extend to other areas affected by the LPA. Some measure of objectivity, scrutiny and review needs to be built into the LPA agreement to avoid the very real possibility of unwitting or malicious manipulation, exploitation and abuse of adults whose capacity will not return and whose access to those who might notice their predicament may be restricted by an individual with legal powers acting apparently in their best interests.

Many people with learning disabilities are already recipients of specialised services and so a provision exists within which structures might be developed to assess and monitor capacity issues, including the activities of those with LPA and general authority.

LACK OF CAPACITY OF THE DONEE

This refers to the person with LPA responsibilities. We have experienced difficulties when the parent of an adult with learning disabilities becomes unwell either through mental health problems or a dementing process. Assessment of the parent can be protracted because understandably they have the same rights to careful evaluation as anyone else. In the meantime the vulnerable and dependent adult may be neglected and sometimes abused. An example is of an elderly woman who began to dement and refused meals-on-wheels and home help for herself and her mid-40s son with learning disabilities and a profound hearing problem who was also not allowed to leave the house. Both were undernourished, dirty and had minor infections. There was no legislation that allowed us to remove the son against his will for his own protection or to enter the house without permission. The Bill needs to be sure to make provision for eventualities of this kind so that both vulnerable adults can be properly and lawfully protected.

The LPA can be cancelled or revoked at any time by the donor while they have capacity to do so but it is not clear how this might be assessed nor is there any indication of how LPA might be challenged by someone other than the donor. The commentary makes it clear that a doctor can challenge the donee of General Authority, LPA and Deputy if they are thought to be in breach of their duties but seems to refer to life-sustaining treatment rather than qualitative matters of health, care and welfare. No other health practitioner is mentioned and, since most adults with learning disabilities are more likely to have contact with specialists other than medical practitioners, this seems to be a serious omission.

COURT OF PROTECTION AND THE APPOINTMENT OF DEPUTIES

For some adults with learning disabilities, the Court of Protection is the most likely source of an advocate in respect of capacity issues given that they may be deemed unable to appoint an LPA. For others there is the delicate balance of rights and protections such that principles dictate we should assume capacity—in this case to make an LPA, while experience suggests we should assess any vulnerable adult intending to make a decision of such significance.

While the whole ethos of learning disability services is to promote independence and support people in taking major (and minor) decisions in their lives, the very fact of requiring a service from us suggests that the individual is vulnerable and that the thinking and reasoning necessary to a given decision may be beyond the capabilities of the individual.

Professionals in this field have always walked a delicate path between allowing people to make mistakes and using persuasion to gain cooperation with an assessment process. The draft Bill, in its implicit emphasis on those with a history of capacity and its explicit assumption of capacity, gives no guidance to those of us who need to assume capacity in principle while suspecting incapacity in practice and to find a way of offering assessments of capacity to people whose vulnerability may lead them to make uninformed decisions that would be in line with the content but not the spirit of the Bill. It would be helpful to have acknowledged the particular difficulties associated with those adults whose condition vis a vis capacity is enduring and neither deteriorating nor likely to improve, who have the right to protection from mistakes that may carry serious consequences, but who also have the right not to have their capacity challenged simply because they have a learning disability.

Many adults with learning disabilities are in contact with local specialist services. Structures exist to provide multidisciplinary reviewing of needs and standards. Those for whom a Deputy is appointed by the Court of Protection would seem very likely to be known and so the Deputy might usefully operate within this framework since they too have an obligation to take the views of others into account when making decisions on behalf of the person lacking capacity.

EXAMPLES

Assumption of Capacity

A 21-year-old woman with Down's Syndrome was referred for sterilisation. The Consultant Gynaecologist interviewed her with her mother and she seemed to be clear that sterilisation was what she wanted. Charlie was bright, communicative and self-assured, nevertheless the consultant was concerned that her capacity to consent was being "taken a little too readily". Charlie was referred to the learning disability service where a specialist interview showed that the driving force behind the request for sterilisation was Charlie's mother whose fear of disability extended to telling Charlie that all her babies would be crippled and die in pain. Charlie herself believed that sterilisation was reversible and that she could have children later, saying that she wanted them to be normal and happy "like me". Eliciting this information took 5 hours over three appointments. Charlie has not been sterilised.

Jim was an elderly man who had lived in institutions much of his life. At some stage, a bladder disorder had been suspected and Jim had a cystoscopy under general anaesthetic. Although autistic, Jim was able to describe the main elements of the investigation and was clearly consenting to having the same procedure again. Unfortunately, this took place under local anaesthetic, causing Jim a great deal of discomfort and fear. When further investigations were recommended, Jim refused because of the recent bad experience but because cancer was suspected, the investigation was thought to be essential and in Jim's best interests. A multidisciplinary meeting took responsibility for recommending that the investigation went ahead and specifying that this should be under general anaesthetic. A cancer was found and Jim was treated.

A man with ASD was referred for dental treatment. Paul used language on few occasions and was thought unlikely to have capacity. His community nurse had prepared a booklet for him about the proposed treatment. This contained pictures of Paul, the hospital, the dentist's chair, a nurse, and various other aspects of the procedure. Paul's carers had gone through this with him several times at home, describing each picture and telling Paul what it meant. Paul had said very little. At interview, Paul was anxious, yawning, giggling and clapping at times. He was not able to give a spontaneous account of the information he had been given, nor would he answer any specific questions about it. Looking at his book, Paul again seemed unable to make any relevant comment, at one point closing the book and putting it away. Suddenly however, he produced a sentence in which the key elements of "hospital", "bed" and the death of his parents (both in hospital) were linked. Asked about his teeth, Paul said "let them stay there" and "no hospital", closing the book again. Further details of the interview seemed to show that Paul made a clear link between the dental treatment, the hospital and the death of his parents. He also knew what the dentist intended to do (remove teeth) and declined. Discussion with the dentist concluded that the treatment was not essential, only desirable, and that she could continue to monitor Paul's dental health since he was very amenable to examination.

We agreed to review should treatment become essential. This assessment took over an hour and was based on the skilled input of a community nurse and Paul's carers.

REASONABLE BEHAVIOUR

A woman with Down's Syndrome is living with a paid carer who appears skilled and attentive. However, Jill has had a number of unexplained illnesses, weight loss and a great deal of medical attention to the point where surgery was proposed. At one point Jill said that her carer was injecting her in the abdomen, raising concerns about Munchausen's Syndrome by Proxy. We were not able to get Jill's consent to blood tests without alerting her carer and Jill did not want to consider alternative residential placements, apparently idolising her carer. Our concerns were that the carer had succeeded in convincing a specialist consultant, whose letters expressed his faith in her competence, that Jill was sufficiently ill to require surgery despite the absence of supportive evidence from any other source. Eventually the carer was subtly challenged on the basis of the evidence, Jill began to gain weight, and the consultant was asked to review his position vis a vis a condition he had diagnosed as irreversible on the basis of the carer's history. Jill did not have surgery, she continues to thrive and the carer is closely monitored. This example illustrates the difficulties that might be associated with both the General Authority and the LPA where those given the powers are able to exercise authority without challenge from the vulnerable adult or non-medical professionals who know the person better than the treating clinician.

SUGGESTIONS

- The presumption against incapacity is modified in circumstances where there is good reason to believe that the person's capacity may be compromised. Evidence would include significant intellectual deficit. Skilled assessment of the individual vis a vis the decision in question would be mandatory.
- People with General Authority, LPA, or Deputy responsibilities discharge their duties in cooperation with the appropriate specialist teams.
- Other Professionals, in addition to medical practitioners, are able to challenge the actions of a person with LPA or Deputy duties.
- People with LPA or Deputy responsibilities should not be able to refuse consent to health services that are beneficial and/or quality of life enhancing on behalf of a person lacking capacity without multidisciplinary agreement.
- Explicit provision should be made for adults with severe learning disabilities to have an appropriate representative with regard to consent issues, especially where an LPA cannot be appointed or it is thought inadvisable that the person choose their own.
- Assessment of individuals for capacity to make specific decisions should be carried out by professionals trained in non-contaminating interview techniques. These interviews should be recorded and open to scrutiny.

- Assessments for capacity should be made as close as possible to the moment at which the decision is required so that evaluations of capacity are as current as possible and not reliant on clinicians who may not have the necessary skills or time.
- The decision about capacity will be a joint one involving the treating clinician (or other professional), and the assessor in consultation with others who know the person well. Where treatment is the goal, it can be helpful to think of this as Essential (must be done now), Urgent (necessary in the near future) or Desirable (pre-emptive or preferable) in determining how to exercise a “best interests” judgment.
- Where provisions such as multidisciplinary teams, Adult Protection, specialist advocacy and reviewing structures exist, these should support, inform and monitor the activities of people with General Authority, LPA and Deputy responsibilities.
- Child Protection, Adult Protection, and Vulnerable Witness protocols can inform implementation of the new Bill.

The content of the Draft Bill would benefit from some adjustment in order to achieve its aim in spirit of the balance of protection and independence for vulnerable adults. While user groups are raising objections to certain aspects of it, all seem clear that the status quo is unacceptable and hope to see enactment of a Bill that meets their needs in the near future. The key to achieving the objectives of the Bill would seem to lie not in assigning powers and responsibilities to a single key individual such as an LPA or Court Deputy but in ensuring open, transparent and objective communication among all concerned with the welfare of any vulnerable person. Good models of multidisciplinary practice exist, showing that empowerment of the person fully or partially lacking capacity by means of skilled information giving and support brings benefits well beyond the primary notion of capacity *per se*. This Bill can either make use of these models by integrating with them or it can sit outside creating the potential for unnecessary conflict. We hope for the former.

Dr Suzanne Conboy-Hill

Consultant Psychologist for People with Learning Disabilities

September 2003

Annex 1

LETTER FROM SERVICE USER

Ms Lord expressed her concerns to her counsellor after reading an article in *Community Care*. We asked her if she would like to put these in writing to send with our comments. Ms Lord is an articulate person who takes an interest in national politics and while there are some misunderstandings which her counsellor is helping to unravel, her letter illustrates the anxieties she experiences at the idea of people who do not know her well taking control of her life.

Annex 2

Submitted by Katie Lord

When I read some information on the Incapacity Bill I was disturbed when they said should somebody need an advocate they should be unpaid to ensure that person has no financial interests.

Because it seems to be suggesting that people from social services are being pushed out and that the next time they want to represent a person with learning difficulties ie for instance one of Suzanne's patients it looks to me as if they're insinuating a doctor, psychologist or psychiatrist's opinions no longer counts. I hate to say this but I should like to know one thing; should someone like me or me ever need an advocate is that unpaid advocate who knows the well qualified to help me or represent me?

Andrew Lee says the Bill goes against everything that valuing people stands for well yes in many ways I agree. And it also conflicts with the Human Rights Act 1998. Well I haven't got any information on the Human Rights Act but I would like to find the information. This is another thing I find frustrating. As a person with learning difficulties I don't feel as if I know all my rights—I know that sounds silly. Andrew Lee also says this Bill takes away people's right to chose that's very disturbing. Then he goes on to say if Tony Blair allows it to go through he seriously questions the Prime Minister's commitment to valuing people. Then he goes on to say if the Bill goes through he expects people with learning difficulties to be out on the street. Well I have been out on the street with dangerous people when I was placed in Hove with an unsuitable carer. I hated the place so much I decided I would sleep rough with a total stranger because I couldn't stand where I was living. I never want to be in that situation again. And furthermore, nobody in my situation should have to be faced with that nightmare possibility. This country has a big enough problem with homelessness without turning people with learning difficulties in their millions out on the street.

I don't want this Bill to go through really. A few frightening things have been suggested:

- This Bill takes away people's ability to choose.

- It goes against everything valuing people stand for.
- If the Bill is forced through, people with learning difficulties may end up on the streets.

Once again this Government has failed to recognise the good people with learning difficulties can contribute to our society. We don't all picture ourselves living happily ever after in those big institutions and psychiatric hospitals.

135. Memorandum from the National Care Standards Commission (MIB 1170)

1.1 The National Care Standards Commission (NOSO) was established by Government through the Care Standards Act 2000 and came into operation on 1st April 2002. We are a non-departmental public body accountable to Parliament through the Secretary of State for Health. We regulate social care and private and voluntary healthcare services in England and encourage improvement in the quality of those services.

1.2 The mental incapacity bill is likely to have a significant impact on the services regulated by the NCSC and on some of the NCSC's own decision-making. Some broad examples include:

- Assessment of capacity in relation to tenancy agreements or other contracts signed by service users. This has a bearing on whether care is provided in a service user's own home which in turn affects how the service is regulated by the NCSC.
- Staff employed as carers in relation to service users who lack capacity or sometimes lack capacity (fluctuating capacity) are routinely involved in assisting service users with decision-making on a day to day basis. The Bill and associated Code of Practice will help to provide a yardstick which the NCSC can use when evaluating the service against some of the relevant regulations and standards.
- The new Criminal Offence introduced by the Bill in relation to ill treatment or wilful neglect of a person who lacks capacity will help underpin the Commission's Adult Protection role in partnership with other agencies.

Comments on specific elements of the Bill are as follows:

2. *The key principles (presumption against lack of capacity and best interests principle)*

2.1 These are welcomed by the NCSC as endorsing current good practice. It is valuable to have included the checklist in relation to "best interests" within the draft legislation. In regulated settings the NCSC would wish to see evidence of consultation in line with clause 4(2) including recorded details of the views of those consulted.

2.2 The Assessment of Capacity is a key issue—it is assumed that the Code of Practice will supply more detail as to how to assess the elements listed in clause 2(1) of the Bill. The published decision of the Care Standards Tribunal (*Alternative Futures Limited v National Care Standards Commission*), states that there should have been "an independent assessment of capacity" noting that it is not for the relatives, advocates, the service provider or the NCSC to assess capacity.

2.3 The NCSC would welcome any direction within the Code of Practice as to both how capacity should be assessed and who should do so.

2.4 The issue of independent advocacy is one which the Commission would like to see included as a right within the Bill as a means of bolstering the "best interests" principle in relation to key decision-making. This would assist, for example, in relation to the decision-making about where a person lacking in capacity should live. A recent consultation meeting chaired by the NCSC and attended by a range of advocacy groups and related organizations indicated that there is a significant lack of advocates throughout England.

3. *The General Authority*

3.1 The Commission welcomes the clarification about the lawfulness of informal decision-making on behalf of a person that lacks capacity. This form of decision-making occurs on a day to day basis in care homes across the country. The restrictions on the general authority (clause 7 of the Bill) are viewed as an essential safeguard to ensure that this general authority is not used to support abusive or restrictive practices.

3.2 Some further clarification as to triggers for referring issues to the Court of Protection would be useful. For example, are there certain categories of decision-making that will need to be considered by the Court of Protection, rather than under the general authority or will referral to the Court of Protection only occur when there is a dispute about best interests

4. *Lasting powers of attorney*

4.1 As the lasting power of attorney incorporates decision-making about welfare matters as well as financial matters this may require adjustments within regulated services to ensure that the LPA is involved in matters such as the service user plan, annual reviews etc.

4.2 In order to fulfil its Royal Commission function, the NCSC has also been involved in gathering information as part of care home inspections, about the number of service users subject to power of attorney processes, enduring power of attorney processes and guardianship orders. It may be appropriate to similarly gather information about LPA's following the enactment of the Bill.

5. *New Criminal Offence*

5.1 The new offence is welcomed as enhancing the protection of people who lack capacity. The Commission would favour an extension of this as a criminal offence to ill treat or wilfully neglect any vulnerable adult, not just those who lack capacity. This would help redress the balance between child protection having a statutory basis whilst adult protection does not.

6. *Code of Practice*

6.1 As earlier comments have indicated this would be a key document which the NCSC would wish to have a role in shaping.

6.2 It is anticipated that this initial submission in relation to the bill will be expanded upon following further consultation within the organisation, which it was not possible to complete within the timescale available.

August 2003

136. Memorandum from Miss Eileen Bailey (MIB 1173)

I am writing to give my support to the Mental Incapacity Bill. I have a daughter with severe learning difficulties who is in support accommodation.

Social Services have taken over decisions made for my daughter which I would like to maintain and so is causing me (and my daughter) great emotional distress and problems with Social Services. I welcome the Bill whole-heartedly and hope we don't have to wait too long for it to go through Parliament.

September 2003

137. Memorandum from CARE (MIB 1176)

1. INTRODUCTION TO CARE

1.1 CARE is a charity representing over 100,000 Christian supporters from all denominations throughout the UK. CARE's Public Policy Department acts as a think tank on ethical issues in biology and medicine, as well as in education and social issues. CARE also briefs supporters and Parliamentarians as relevant issues are considered in Westminster, Brussels and the devolved Parliaments and Assemblies.

CARE has been following the issue of Mental Incapacity since the original Law Society discussion document of January 1989 and the subsequent Law Commission Consultation Paper of April 1991. Since then CARE has regularly submitted written evidence and discussed these matters at meetings with officials and Ministers. CARE has been a participant at recent seminars at the Lord Chancellors Department. In addition, CARE has made submissions at a number of previous stages in the process which has led to this consultation, most recently in June 2002 on the guidance leaflets which were "setting the scene for new legislation". This reply is not confidential.

2. GENERAL COMMENTS

2.1 CARE recognises that there are deficiencies and problems with the current legal framework and acknowledges the substantial work undertaken by the Department for Constitutional Affairs and its predecessor in considering some of these issues. CARE believes that persons who lack capacity are disadvantaged and vulnerable, and deserve the highest level of protection and support which an advanced society can give to them.

2.2 CARE acknowledges the differing pieces of historic legislation currently applied to these issues and recognises that an overall, rather than a piecemeal approach, would be of benefit. However, any new procedures should be flexible, easy to use and financially beneficial while providing strong safeguards for the more vulnerable members of society.

3. ADVANCE DECISIONS

3.1 CARE wants to involve patients in decisions about their own healthcare as much as possible, and therefore supports the principle of advance directives to the extent that they can extend patient involvement into decisions after the onset of incapacity. However there are dangers in the “piece of paper” approach. By the time an individual’s incapacity triggers an advance directive, the situation may not be precisely what was envisaged, new treatments may have come into being, and most important of all, the healthy do not make their choices about healthcare in the same way as the sick. Health professionals cannot know whether the individual might have “changed their mind”, and as capacity is required to revoke an advance decision, the incapacitated person is trapped in the consequences of a previous decision. Advance decisions will force doctors and nurses to practise with one hand tied behind their backs, and should not be given the further force of statute law.

3.2 CARE has a second area of concern—the possibility of advance directives, which have statutory force, becoming a back door route into euthanasia. Advance directives, while having some force in law, cannot be used to force a doctor to do something which would otherwise be unlawful. However the worldwide euthanasia movement has been at the forefront of promoting the use of advance directives. For some who support euthanasia, the acceptance of such documents in statute law, complete with a request for the withdrawal of nutrition and hydration, are an essential step in the campaign to change the law. CARE is concerned that such slow deaths could be enforced under the proposed legislation, under the terms of certain advance directives, or at the order of the donee of an LPA.

3.3 The House of Lords Select Committee on Medical Ethics reporting in 1994 opposed giving advance decisions greater legal force as this would risk “depriving patients of the benefit of the doctor’s professional expertise and of new treatment and procedures which may have become available since the Advance Directive was signed”. In its legislation on mental incapacity (2000), Scotland has not given Advance Decisions statute force and is managing well without this. CARE holds that all the proposals on advance decisions should be removed before legislation.

4. WITHDRAWAL OF FOOD AND FLUID

4.1 The concern just highlighted could be eliminated, and some material on Advance Decisions could perhaps be left in, if the Bill were to incorporate new legislation to prevent the withdrawal of food and fluid with the intention of ending life or hastening its end.

4.2 This issue has been the subject of much discussion in the House of Lords during the recent debate surrounding the Patients’ Protection Bill as tabled by the Baroness Knight of Collingtree. The Committee should consider if the current Bill would benefit from the wording of the recent amendment tabled by both Baroness Knight and Baroness Finlay of Llandaff to the Patient Protection Bill, Amendment No 1 (4 July 2003):

EXCEPTIONS TO SECTION

(1) No offence will have been committed under section 1(1) if any of the requirements in subsections (2) and (3) below are met.

(2) The patient—

- (a) requests the withdrawing or withholding of sustenance;
- (b) does not give consent to the provision of sustenance; or
- (c) does not give consent to the recommended intervention to provide sustenance.

(3) In the case of a patient who lacks capacity to consent, consultation by the doctor in charge with the next of kin or legally appointed representative has taken place, and the provision of sustenance—

- (a) is likely to cause significant discomfort to the patient without improvement in his condition, or worsen his illness or debility; or
- (b) is likely to result in no improvement in the illness or debility of a dying patient.

(4) For the purposes of subsection (3) a patient lacks capacity if he is unable to understand in broad terms the nature and effect of the decision to withdraw or withhold sustenance.

4.3 New legislation should enshrine the prohibition of intentional killing by omission (withdrawal of food and fluids from the non-dying). CARE's concerns at (3) about Advance Decisions would then substantially be met.

5. EXCLUDED DECISIONS

5.1 CARE welcomes those excluded decisions listed in Clauses 26–29, but believes that because they are central health and family issues, the following should be added:

- Termination of pregnancy.
- Sterilisation.
- Long term depot contraception.

These are issues with permanent consequences which are very important to the health and social well being of some incapacitated people. The medical and ethical aspects need addressing specifically. Detailed consideration might be provided for in the Codes of Practice described in Clause 30, if there were specific mention of the concepts in "Excluded decisions".

6. THE COURT OF PROTECTION

6.1 CARE's particular concerns with the proposed legislation are around healthcare issues, and while welcoming the concept of the new Court of Protection, CARE recommends that judges and staff involved with the Court should receive specific training in healthcare ethics and practice. This training would be similar to the Judicial Studies Boards organised by the Lord Chancellor's Office for members of the judiciary. This latter point is particularly important, as legal officials must be fully aware of the practical consequences of the decisions they take. They need to know what actually happens in the real world of health and social services.

7. CONCLUSION

7.1 CARE is grateful for the opportunity to make this response, and is willing to help with oral evidence if requested.

September 2003

138. Further supplementary memorandum from the Lord Filkin (MIB 1225)

JOINT COMMITTEE ON THE DRAFT MENTAL INCAPACITY BILL: ACCESS TO INFORMATION & JURISDICTIONAL MATTERS

Thank you for the letter of 28 October asking for clarification on access to information issues related to the draft Mental Incapacity Bill. I am replying to this request here and I also include further information on jurisdictional matters that were requested at the oral evidence session on 22 October.

ACCESS TO INFORMATION

We are well aware that matters relating to access to information, confidentiality and data protection are both important and difficult for those who lack capacity. These issues do not feature explicitly in the current draft of the Bill because they will largely be dealt with by consequential amendments and by guidance. Consequential amendments will be included in the Bill for introduction.

Guidance issued by the Information Commissioner currently advises that where there is an Enduring Power of Attorney or authority from the Court of Protection, it is possible to make a subject access request, under the provisions of the Data Protection Act 1998, on behalf of someone who lacks mental capacity. Whilst the EPA relates to the management of a person's affairs, the Information Commissioner's guidance is, we believe, an acknowledgement that the management of affairs may require access to clinical records, but it would be wrong to assume that this will always encompass decisions about treatment and care. There is also a Data Protection (Subject Access Modification) (Health) Order 2000 SI 2000/413 and a Data Protection (Subject Access Modification) (Social Work) Order 2000 SI 2000/415 that make reference to court appointed representatives being able to make a subject access request on behalf of someone who is incapable, provided that certain information is not disclosed to the representatives.

As the Mental Incapacity Bill will introduce new wider functions of Lasting Powers of Attorney and deputies we intend to consult the Information Commissioner about the possibility of amending his guidance accordingly. The intention is to allow LPAs and deputies to make subject access requests where appropriate.

Consideration is being given to the extent to which financial LPAs should be able to access health and welfare information and vice versa. We will also revisit the 2000 Orders and consider whether these will require amendment in the light of the Bill.

We also propose to include in the Bill a similar power as provided by the Adults with Incapacity (Scotland) Act 2000 in relation to the health records of deceased individuals. This will enable those acting on behalf of persons without capacity who have an interest in the estate of a deceased person to access health records under the existing provisions in the Access to Health Records Act 1990.

As now, under the Bill, registers of LPAs and deputies held by the Public Guardian will be searchable by the public so that it is possible to find out who has authority in a particular case.

Access to information under the General Authority is more difficult because there is not one clear person with authority to act. Here we are dealing with the same situation as that which exists under the current common law. At present information is shared on a “need to know” basis and guidance for NHS staff, “Confidentiality: NHS Code of Practice”, has now been published following a public consultation. The Code has been endorsed by the British Medical Association, General Medical Council and the Information Commissioner and can be found at www.doh.gov.uk/confiden. Health and social care organisations operating under best practice have drawn up information sharing protocols. For example, the “No Secrets” document requires Adult Protection Committees to draw up common agreements relating to confidentiality.

Where information is held under the common law duty of confidentiality, it must only be disclosed for the purposes that it was collected for unless there is explicit consent from the subject, a statutory basis for disclosure or a robust public interest justification for the disclosure. Regarding this latter justification, it is accepted that where there are concerns about abuse and vulnerable people are at risk, then absolute guarantees of confidentiality cannot be given.

Our developing work on the Bill is leading us to examine further whether these current arrangements on information sharing would be adequate under the Bill, perhaps supplemented by clear guidance, or whether the Bill justifies a fresh look at these policies. We will continue to investigate this.

JURISDICTIONAL ISSUES

On 22 October Mrs Humble raised the question of what would happen under the Bill to an incapacitated person on vacation in Scotland who suffers an acute episode of a terminal illness and is hospitalised in Scotland. We undertook to provide more information on this point.

Here our intention is to provide rules in the Bill to match those in the Adults with Incapacity (Scotland) Act 2000 and to be consistent with the Hague Convention on the International Protection of Adults 2000. These provisions on Private International Law are technical and will be included in the Bill for introduction.

In relation to the Lasting Power of Attorney, the general position would be that an attorney appointed in England would be able to act on the incapacitated adult’s behalf in Scotland. In general the law that applies would be that of the incapacitated adult’s habitual residence at the time when the LPA was made. English law would be applied to matters such as whether the LPA is valid. However, the manner in which the attorney can make his decisions is likely to be governed by Scottish law.

In relation to the application of the advance directive, the Scottish administrative and judicial authorities generally would apply Scottish law. The authorities are empowered to apply the law of England and Wales if it is in the adult’s best interests and if the circumstances demonstrate a substantial connection to England and Wales. The Scottish authorities would take an overall view of the situation. It may be more likely, where it is an emergency situation, that Scotland would take a pragmatic approach and apply its own law. That would mean the doctor in charge doing what is reasonable in the circumstances although the incapacitated adult’s representative could apply to court for an order if they wished to do so.

I hope that this response adequately addresses your concerns. If you should require any further clarification please do not hesitate to ask. I am copying this letter to Rosie Winterton.

Geoffrey Filkin

November 2003

139. Supplementary memorandum from Mr Roger Goss, Patient Concern (MIB 1195)

I attach the two proposed amendments to the Bill we were invited to submit by the Chairman of the Joint Scrutiny Committee during our oral evidence on 16 September.

I mentioned during my evidence that the BMA want the requirement to *explicitly* give LPAs power to make end of life decisions removed. (Clause 10) They argue that the absence of such a power would mean clinicians going on giving treatment when of no benefit. Clinicians would have to assume they should carry on rather than stop.

We oppose this suggestion for two reasons:

- We believe the real reason for their objection is the natural and usual desire of the BMA to protect clinicians freedom of judgement to do as they consider fit, unhampered by patients explicit instructions.
- Because of the gravity of deciding to grant end of life decisions to someone you trust to act in accordance with your beliefs, values and priorities, we consider granting it *explicitly* a sensible safeguard against a poorly written and ambiguous LPA.

September 2003

Annex

**Specific amendments for improving the Draft Bill suggested by Patient Concern
(founder member of the Making Decisions Alliance)**

Tuesday, 16 September 2003

These suggested amendments reflect the reactions of patient concern's special advisory board to the draft bill and my 10 years' experience dealing with issues around advance refusals of treatment.

AMENDMENT 1

Please give serious consideration to removing sub-clause 4 c of clause 24. However well-intentioned this safeguard, it threatens the enforceability of all advance refusals on the basis of pure speculation. We appreciate the desire to protect people from missing out on new successful treatments.

If that is this safeguard's objective, please say so "in terms". If this is still considered insufficient protection from missing out on some brilliant new intervention, then consider making it a legal requirement for an advance refusal to have been made, or updated, within the last x years of becoming applicable.

Please keep in mind two realities. Firstly, as we have discovered from the many calls to our helpline, e-mails, and letters, some clinicians understandably find it difficult to accept a "thanks but no thanks". The BMA acknowledges this problem in their guidance on advance statements.

Secondly, the ultimate purpose of this legislation includes facilitating the right to make an advance refusal for any, no or an apparently irrational reason. It is also about protecting our right to risk making our own mistakes, rather than promoting paternalism, however well intended.

AMENDMENT 2

Please give serious consideration to including a proforma advance statement in a schedule to the bill.

Nine out of 10 people are unfamiliar with this common law right. Many healthcare professionals are unclear on the legal enforceability of valid refusals of treatment. Some lawyers have only the vaguest notion of their legal status.

Including a proforma in the bill, rather than leaving it to codes of practice or guidance, such as produced by Patient Concern, would perform an invaluable educational role. It would act as a visual aid to helping people to envisage the form a statement can take. It could also suggest a structure that incorporates useful safeguards such as two independent witnesses. These could certify that they are not aware of undue pressure on its author to make a statement and that they have no interest in its implementation.

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